

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

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

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

All written material should be in the English language and may be edited before publication.

It should be sent for publication to arrive by the date below.

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

DbI Review is also available in Spanish or on disk.

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Cover: French CHARGE Meeting

A message from the president

A warm welcome to all our new members and thank you all – new and old – for your continued support for Dbl.

As I write this I hope that many of our members will be busy registering or submitting their abstracts for the next Dbl European Conference planned for August next year! The doors are open for everyone wishing to participate in this exciting conference and to benefit from what seems to be an excellent programme and setting. I know that everyone is working very hard and arrangements are well under way to ensure your comfort and full participation!

Security concerns have caused the postponement of the Asian conference, but plans are in place to go ahead in another location at the beginning of 2006.

Your Management Committee had the pleasure to meet the representatives from Senses, the organisation hosting the next world conference planned for 2007 in Perth, Western Australia. We were all very impressed with the preparation already underway. I will be going, with Richard, to meet the local Planning Committee in February 2005. We will also have the opportunity to meet the wider team of people involved in this great event and service providers in this area.

In response to our recent call for support I am happy to say that we have already received three applications of interest to host the 2009 European conference. We look forward to moving this forward.

We continue to have a cordial and productive relationship with the World Federation of the Deafblind (WFDB), where we are fortunate to have a member attending our Council meetings. And we are in the process of drawing up a Memorandum of Understanding with the International Council for Education of People with Visual Impairment. (ICEVI). Mike Collins is the Dbl representative on this organisation. I will be attending the WFDB General Assembly and World Conference next year.

Networking and network development is a priority of Dbl and this remains a core activity of our recognised groups. We are looking for Network co-ordinators in two established and important areas – Staff Development and Employment. If you are interested get in touch with Anny Koppen, her address is on the back page.

I was invited by the Nordic Staff Training Centre (NUD) to their Conference in Iceland. Over 150 staff from the five Nordic countries came together for an extremely stimulating and well organised conference. The Norwegian Association of the Deafblind's annual meeting was yet another highlight this year.

The things that remain in my mind are the places I have visited and the incredible range of people, services and interests of our membership. So many dedicated

professionals, deafblind people themselves and family members are a credit to our field and I am proud to hear they feel at home in our organisation.

I hope to see you in 2005!

William

Editorial

What variety we have for you in this edition! We have truly inspiring people talking about their work or being spoken of about by people who admire and support them. Ezekiel Kumwenda for example, became deafblind very suddenly but did not allow this to hold him back from achieving recognition in his country. He has chosen to work for the rights for disabled people and in particular those who are deafblind. Devi Amala, from Southern India, is another success story. Once her deafblindness was recognised and a programme of learning put in place to meet her needs she has just “taken off”. She is a happy and very successful young person and her family is proud of her achievements.

I had a wonderful surprise this summer when I found that Jan and Graham Scahill had arrived on holiday from New Zealand. I have been carrying on a “e” friendship with them for many years – reporting to them about life here and hearing about the NZ organisation, and all its activities, in return. In spite of having the holiday de-railed by an accident to Graham they were as cheerful as ever and it was really good to catch up with them. So hello New Zealand!

Talking of intrepid travellers... the holiday, specially for deafblind people, was hosted in Sweden this year – a great time had by all – and the venue for next year – Bulgaria – has already been fixed with a host of opportunities planned.

You’ll be interested to know that we will be trying to push forward with the website as soon as funds allow. Patience is required at present, but I’m sure the planning and consulting we are doing will produce a better result for the long term.

I always I look forward to hearing from you and sharing your work with others through the magazine or the website.

Eileen

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Working with Voluntary Employees

In this article Stefan Spring and Catherine Woodtli describe the ground-breaking experiences of the SZB Counselling Services in developing the concept of voluntary employment and providing the evidence of its success.

The Counselling Services for Deafblind people of the Swiss National Association for the Blind (SZB) offer social counselling, rehabilitation training and socio-cultural activities to deafblind and hearing and visually impaired people in Switzerland who are not in hospital. Most clients have acquired deafblindness.

In many situations the visually and hearing impaired require one-to-one support for mobility, communication and gaining access to information. Social counsellors do not have time to accompany their clients to events, on holidays or other occasions and this is not their job anyway. On the other hand, relatives are not always available for such tasks and in some cases clients prefer a more neutral person to accompany them. In Switzerland there are still no professional assistance services. For this reason, the SZB strongly promoted its cooperation with voluntary employees and, as a result, has developed a modern concept. The concept is subdivided into the following areas:

- Recruitment of new voluntary employees
- Introduction and aptitude testing
- Training and further education
- Organisation of assignments and taking care of voluntary employees
- Checking the performance of voluntary employees

Voluntary employees' mission

Voluntary employees work on behalf of the SZB and are assigned a specific mission. The voluntary employees should empower the deafblind or visually and hearing impaired person to reach her goal by providing reliable company and the necessary assistance. In doing so, the person's own wishes (for instance, to participate actively or passively in an event, to continue or to stop a task etc.) must always be respected.

Activities include:

- Accompanying visually and hearing impaired or deafblind people to the doctor, acoustician, therapist or physiotherapist, on shopping tours, visits, walks, sporting activities, trips or to seminars, congresses and other activities of self-help organisations of deafblind people etc.
- Accompanying visually

and hearing impaired or deafblind people to events organised as part of the SZB's annual programme, such as group meetings, courses, workshops, parties, excursions, holidays etc.

- Assignments as part of projects without direct contact with visually and hearing impaired or deafblind people (secretarial work, driving services, sale of handicraft products etc.)

Results in numbers

The SZB Counselling Services for Deafblind People can rely on around 170 voluntary employees. In total these people worked 12,726 hours in 2003. Given the size of Switzerland this is a very impressive amount of hours and corresponds to an increase of 13% as compared to 2002. Expressed in full-time jobs, these hours are equivalent to 7 jobs on the basis of 100% productivity! And what is especially important for the SZB: to carry out this amount of work the SZB would have required 12 to 14 permanent employees. A translation into Swiss Francs demonstrates that those who donate time are rightly considered to be the most generous donors (value: 1.2 to 1.5 m CHF = approx. 800,000 to 1 m euros). A breakdown of the hours worked indicates that the largest part is owed to a group of voluntary employees who work between 150 and 300 hours per year which corresponds to half a day per week and is thus in line with the recommendations of modern voluntary work.

In 2003 voluntary employees were offered 14 training days, which were attended by a total of 150 people. The SZB spent a total of 2,248 working hours organising voluntary work and training in 2003 and invested approximately 146,000 CHF (about 97,000 euros) in travelling expenses, training and further training as well as recruiting voluntary staff. The following chart reflects the positive result of this work:

Voluntary work organised by the SZB Counselling Services for Deafblind People serves as an example throughout Switzerland. In 2005 the concept of the SZB and its respective tools with regard to further training will be made available to all Swiss organisations involved in work with visually and hearing impaired and deafblind people.

Stefan Spring
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Supporting deafblind people in Malawi

This is the story of a remarkable man, Ezekiel Kumwenda, and his determination to increase awareness and develop services for deafblind people in Malawi

My name is Ezekiel Kumwenda. I was born on 5th May 1970 and I lost my sight and hearing on 9th July 1990. This was the period when I was in form 3 at Chichili Secondary School. One morning when I was in class, I experienced a severe headache. The headache persisted and I was admitted to Queen Elizabeth Central Hospital for some time before I was diagnosed as having a brain tumour that needed surgery in South Africa. Due to the tumour, I started losing sight and hearing – both gradually deteriorated. However, not all was lost as grace was with me. With divine providence, I survived one of the most critical brain surgeries at Garden City Clinic in South Africa and pulled through.

Although the tumour was removed, my sight and hearing were not fully recovered. I found myself in the category of people with visual and hearing impairments. Malawi's population has quite a considerable percentage of visually impaired people, as well as the totally blind and hearing people. I had to be considered for another school when I recovered, since I now did not have full sight and hearing. After a lengthy discussion, I was transferred to St Patrick's Secondary School in Blantyre where there are facilities for blind students only. At first, it was quite tough to live as a blind and hearing-impaired person after once enjoying the privilege of sight. I had to learn Braille. I encountered a lot of problems – for instance in class I could not take down notes and could not hear the teacher as he/she taught but I had to sit for the same examinations as the other normal students. I realised that there were several other students across the face of the country who were facing the same kind of injustices and inconsiderate treatment, without their voices being heard.

In 1995, I brought together a number of blind students throughout the country to discuss their plight in relation to education in the country. As a result of the meeting, the Students Union for the Blind was formed, to act as a voice for the visually impaired students in the country and aimed at addressing issues relating to their education.

In 2000, I was elected as the president of the Malawi Union of the Blind. Whilst serving as the president of the Union, I realised that there was a group of people who needed special attention and who were, like myself, Deafblind. Neither the Malawi government nor the private sector has services for these people.

In 2001, I pioneered a group of people to form Visual Hearing Impairment of Malawi, whose mission was to open the eyes of the authorities so that Deafblind brothers and sisters could begin to see the light at the end of the tunnel. Malawi

has indeed a very substantial number of people with deafblindness and neither the government nor the private sector has services for them. The principal services of the Visual Hearing Impairment of Malawi (VIHEMA) are advocacy, rehabilitation, vocational training, independent living and economic empowerment.

Since the formation of this organisation, tremendous achievements have been made – for example, a deafblind unit at Mount Fort Demonstration school in Nguludi has been established, where five children have been enrolled. Now that the welfare of the deafblind will be looked into by VIHEMA, we are looking for partnership support in the form of advice, finance, and technical guidelines with regard to baseline survey and the provision of a short-term expert in deafblindness for our organisation, to do fundraising research.

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Please contact Ezekiel if you would like to hear more about his work or you feel you could offer support to VIHEMA

The 8th European Holiday for Deafblind People

Bulgaria, July 2005

Dear Friends,

We are looking forward to your application to participate in this carefully organized programme. It has been prepared by the National Association of the Deafblind in Bulgaria, in cooperation with the Union of the Blind.

I hope to meet you all in Bulgaria!

Dimitar Parapanov, President of the National Association of the Deafblind in Bulgaria

The Place: the city of Varna, big sea resort on the Black Sea. There is an International Airport at Varna, a railway station and a bus station.

Accommodation: The Boarding School for Children with Impaired Vision – Varna, located in beautiful and calm forest, 10 minutes walking distance from the beach and 20 minutes walking distance from the city. Double rooms, each with its own toilet and shower/bath (hot and cold water).

Duration: 7 days

Price: Board and lodging in double rooms, transportation in Varna and Excursions and all the respective entertainment in the programme – 290 Euro per person.

Do you want to know more? More information with details, programme, application etc. will be available in January 2005.

If you have any questions or would like to apply please contact: nadbbg@mbox.digsys.bg

Developing the potential of deafblind children – from personal experience

In this article Nina Akuorkor Afutu describes her personal experiences from her work with deafblind children in Ghana

Disability comes in different forms. There are single disabilities like deafness, blindness and mental retardation, but one group of people with multiple disabilities is those with deafblindness. Many people think that people with deafblindness are unable to take an active part in life, which is not the case at all. For the five years that I have worked with deafblind people, I have realised that they have abilities, potential and the capability to do a lot to improve their lives when given the requisite support in terms of human and material resources.

Realising potential

When I first entered a classroom of deafblind people to teach, especially the totally deafblind, I found it very challenging. Help came in the form of a colleague who, having been doing the job for some time, offered some guidelines. When I applied these guidelines and the techniques this colleague shared with me, I found teaching and learning with this group of children interesting.

The following are some of the things I would suggest for teaching deafblind people:

- One needs a lot of patience, love, and time to achieve good results.
- The major avenues (senses) through which effective learning takes place are sight and hearing. When these senses are impaired one finds it very difficult to get connected to the environment. This is the situation in which persons with deafblindness find themselves. Therefore, in the teaching and learning process of the deafblind, all modes of communication should be used, based on the needs and abilities of the person (Miles & Riggio, 1999), for information to be received and expressed.
- One needs to take into consideration the deafblind person's level of ability, and the strength and pace at which he/she can learn, before tasks are given.
- Involving the deafblind child in every activity or task is very important.
- Tasks or activities must be broken down into small targets to allow for concept formation and the grasping of necessary skills.
- Similarly, routine tasks or activities must be constantly practised as this goes a long way to broaden and widen scope and learning.

- A variety of teaching strategies should be incorporated, such as task analysis, motivation, use of a variety of objects or materials, pictures, models, Tadoma, sign or tactile sign, Braille and finger-spelling – all of which make teaching and learning very motivating and lively.
- Motivation in terms of praise or rewards like patting, clapping or shaking the child's hand and other appreciative gestures must always be given for the attempted performance of a task. The deafblind child or person becomes very happy when such incentives are offered and wants to repeat the activity or work more when asked to do so.
- The attention span of most deafblind persons is limited; for that reason periods for performing tasks should not be too long. This avoids the deafblind person becoming bored and losing interest in the work.
- Objects and materials should be used widely as they bring a lot of joy.
- For teaching and learning to be effective and interesting it is important to break down any boredom, tiredness or refusal to do a particular task by giving the child a short time to relax, or take the child for a walk round the school premises which will be refreshing. If all these strategies fail, change the task.
- Include short field trips, or educational trips, in and around the environment in which they learn, as these are motivating for both the teacher and the child.
- The use of the calendar system makes teaching and learning very effective and meaningful to the child. This approach helps the child to anticipate events, become time conscious and establish a sequential way of performing daily activities. Majors (1999) pointed out that the use of the calendar system is an effective and recommendable strategy.
- Allow choice-making in a calendar or schedule box as this strategy enhances learning.
- Lastly, in teaching deafblind children there is nothing like instant satisfaction, as compared to teaching in the regular educational setting. Satisfaction only comes the day the deafblind person can perform a task independently. It is then that the deafblind person as well as the teacher can become very happy because learning has taken place.

Conclusion

The different techniques outlined for teaching persons with deafblindness, when applied, will make teaching these children flexible, easy, very interesting and enjoyable. Parents, guardians and all who come in contact with the deafblind are advised to help promote learning in deafblind persons using the positive strategies outlined as this would go a long way to offer them a position on the educational ladder.

References

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Miles, B. & Riggio, M., (1999). Remarkable Conversations. A guide to developing meaningful communication with children and young adults who are deafblind. U.S.A. Conrad N. Hilton Foundation.

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Asante Boateng – a talented student

Nina writes:

Asante Boateng is a congenitally deafblind young person who studies at the Centre. He came at the age of five and he is now fourteen years old. He is mobile to some extent and we think he is brilliant!

He is taking schools programmes like simple numeracy in counting, reading simple words and spelling, and also tactile signing, cooking, personal hygiene, mobility, and daily living or independent living skills and Braille.

He is also talented and is developing vocational skills. He does doormat weaving, weaving of table runners, and fluffy ball making.

Institutions and services for deafblind people in France

This is the first in a series of articles about the French organisations and Jacques Souriau introduces the series to us.

Most organisations that operate in the field of deafblindness in France are represented within DbI by the ANSPA (l'Association Nationale pour les Sourd-Aveugles – The National Association for the Deaf-Blind), which collects funds from these organisations enabling them to be members of DbI. So I thought it would be interesting and useful to present, by means of a series of articles, the different people involved in the world of deafblindness in France.

There are about 20 institutions in France where deaf-blind people can be accommodated, in addition to support services for local community work. These facilities cover a vast range of services: early education, schooling, facilities for those who are dependant, protected work places, support for autonomy in the home, elderly people etc. Several associations contribute to the creation, organisation and everyday activities of these services.

I intend to explain this group as a whole in 4 articles which will focus on:

- The work of National Association for the Deaf-Blind (ANPSA)

- Services for children
- Services for adults
- The “Centre de Resources” (Resource Centre) and its current projects

In each article the administrative associations that take care of the running of these services will also be presented by means of inserts.

In this first article I have asked Jean-Marc Cluet, the current president of the ANPSA, and also the Director of the Chevreuse, an institution for deafblind children, near Paris, to tell us about this association. He does this with the help of Annie Van Espen, who is deaf and blind, and Régine Larson, mother of a young deafblind daughter.

We also hear about the association that runs the Chevreuse, “l’Entraide Universitaire” (University Self Help) from Jean-Philippe Verdier, who is an administrator and representative with ANPSA.

ANPSA: The National Association for the Deafblind

ANPSA, National Association for the Deaf-Blind, was founded in December 1978 by parents and professionals who wanted the needs of deafblind people to be better known and for activities to be better co-ordinated.

ANPSA is made up of six groups:

- Deafblind people
- The legal representatives of those who are under age or in care
- Members of their families
- Friends
- Professional people
- The administrative associations

Until now, there had been no association for the deafblind in France and the ANPSA is now the reference body for all those affected by deaf-blindness.

ANPSA structures itself around the following activities:

- The edition of an information bulletin: the “Bulletin de l’ANPSA” (the ANPSA bulletin), which comes out once every 3 months in Braille and in enlarged, black print.
- An annual meeting for deafblind people, including a leisure programme and discussion workshops.
- A secretarial office providing regular information for families and deafblind people about their rights and about the services or institutions that are available and accessible.
- ANPSA defends the needs and expectations of the deafblind to the authorities and other associations that act for other types of handicap.

- ANPSA supports development projects and projects for the creation of institutions and services.
- It provides information for both professional people and organisations.

The annual meeting for the deafblind is considered by ANPSA to be an essential event. This is confirmed by Régine Larson, mother of Annabelle, a young deaf-blind girl who lives in Poitiers and works at the CAT for the deafblind at La CHAUME. Régine has always been very active within ANPSA and has organised the annual meeting for the deafblind for two years now.

She says: “Each year this meeting is the occasion for people who are geographically far away from one another to be reunited. The preparation for this event, throughout the year, also gives deafblind people the chance to work together and to keep in touch. For many of the participants it is one of the main events of the year and for some it is even the only opportunity they have to move out of their tiny everyday circle and to cultivate long-lasting friendships, which encourages them to write to one another throughout the rest of the year.

The meeting takes place in a different place each year, chosen exclusively by the deafblind people. In this way the participants can gradually get to know different parts of their country. These cultural and tourist visits make the ideal environment which the deafblind enjoy most: discussions, chats and parties. At the end of the trip they return home with a store of happy memories that will encourage them in their preparations for the following reunion and in their letter-writing.”

Deaf, blind and suffering from Usher syndrome, Annie Van Espen has been a member of ANPSA since 1984 and of the Board of Directors since 1987. She would like to share with us what the ANPSA means to her. “25 years ago, because of the restrictions caused by my sensory deficiencies, my parents tried to find opportunities for me to get out and about, so I tried to find an association that I could take part in. It was difficult at first because all the associations brought up the question of my second handicap: for the deaf I could not see and for the blind I could not hear. In 1984 I tried to participate in the annual deafblind meeting in Villebon and that is where I began to get to know the deafblind. Gradually I began to take more of an interest in the group and I made progress in communicating with other deafblind people. I became less shy. I find this is really the association best adapted to my problem. Out of all the ANPSA activities, the annual reunion is the most important and that is where I met my husband.

I would like to see the ANPSA developed further. It is still only a small association and does not have enough members. I would like cultural, manual and artistic activities to be provided, as well as sports activities, just as there are in French-speaking Switzerland, to bring the deafblind closer together. In France there are not enough of these activities.”

Next December ANPSA celebrates its 26th anniversary.

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Entraide Universitaire

Mr Jean-Philippe Verdier, administrator of the Entraide Universitaire, tells us about his association:

“The Entraide Universitaire was created in 1954 by the Mutuelle Assurances Elèves (a mutual accident insurance company for children at school in the Paris Region). This association created its first activities for the children it insured: educational school trips to the sea and to the mountains. The association then gradually turned its attention to disabled children. It took an interest, first of all, in children in social difficulty, creating foster homes for children and hostels for teenagers. It then turned to the mentally handicapped, creating, in the 1970’s, the first CAMSP (Centre d’Action Medico-Social Précoce – Early Intervention Centre) in France (where some deafblind children were accommodated) and CAT’s (Centres d’Aide par le Travail – sheltered workshops). In the 1980’s, the Entraide Universitaire began to help those with sensory handicaps. In 1982 it created an institute for deafblind children in Chevreuse (in the Paris region) and in 1986 the CAT Jean Moulin (which, in the beginning, accommodated deafblind people). Finally, in Vélizy (Paris Region), in May 2000 and in 2001 respectively, group homes and a CAT (sheltered workshop) came into being. These latter projects were intended to accommodate young adults from the Chevreuse institute for deafblind children as well as people from other regions. Today, the Entraide Universitaire manages 35 institutes in 25 different locations.”

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Working in the community with deafblind young people

In this article Leela Agnes, from the Holy Cross Service Society in Trichy, India, describes the huge success that Devi Amala, one of the young people that their service supports, has achieved. With specialist support from the Holy Cross programme, and with her family on board, she has transformed her own life and, in doing so, has become a much happier person and a proud and valued member of her family and local community.

Devi Amala is a 17-year-old deafblind girl. Our community-based field worker met her when she was 15 years old, through a village leader who was able to see that she needed some support. Devi has profound deafness, micro cornea, nystagmus and a heart problem.

During our initial visit to Devi Amala's house, we found that her family members neglected her. She spent most of her time sitting in a corner doing nothing, and she hated people and never allowed anyone, other than her mother and two brothers, into her house. She was totally dependent on her mother for all her daily needs, and there was no means of communication between her and her family members. She behaved like someone who had serious cognitive difficulties.

So we took the decision to focus on training in life-oriented skills and some objectives were set. After some work, a rapport developed between the field worker and the girl, and we saw Devi Amala's eagerness to learn and the development of her interests.

After two years of training, Devi Amala is now totally independent in daily living skills. She uses sign and gestures for communication. Basic reading and writing skills training was given and she now knows to write her house address, the names of family members, names of vegetables, vehicles, household articles, shapes, colours, etc., She can finger spell Tamil Alphabet letters. Number concepts have been introduced and she knows how to do two digit addition sums.

Devi Amala's mother was proud and happy when she began to learn and to share the responsibility of household activities! Devi Amala fetches water from a nearby public tap, washes clothes, washes vessels, sweeps and mops the floor of the house, folds mats and arranges and maintains household materials. She can prepare tea, boil rice and fry vegetables. The work she does is very neat and tidy and her mother was even more proud because her daughter achieved the duties of a Tamil lady. Every morning Devi Amala cleans the front portion of the house and draws a beautiful kollam on the floor (Kollam is a Tamil traditional and cultural task which has to be done every day in the early morning).

Community members around Devi Amala's village do textile work for their living so we decided to give the same type of job to Devi Amala. Her mother took the

responsibility of providing vocational training for her daughter and approached a small-scale cottage industry to supply towels and trained Devi Amala to do tassel work on the towel. Devi Amala now works independently and does the work regularly and with great skill and care. She earns enough to make a big economic contribution to the income of this poor family.

Devi Amala's mother said that she never expected her daughter would be able to do domestic activities and a paid job and become a useful person in the family. She also said, "My child never allowed relatives and friends inside the house, which disturbed our relationships with others, but now she is very sociable and shows hospitality by serving tea and trying to communicate with every guest". She expressed this with a deep feeling of happiness. Devi Amala's mother also said that she used to have to support her with every area of personal care. Now, after receiving orientation and mobility training, she is independent enough to undertake all this on her own – even when there is a walk involved – which is a big relief for her mother. Now her mother, who was always hearing criticism from her neighbours about Devi Amala's lack of progress, can talk proudly about her skills in spite of her disability, as Amala does all her routine activities properly and on time!

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France
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C/o Ricard Lopez
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ESP-08014, Barcelona, Spain
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Email: talking3@teleline.es

European Usher Syndrome NETWORK (EUSN)
C/o Carol Brill
500 Ballinteer Road, Dundrum
Dublin 16, IRELAND
Tel:+353-1295-1387
Email: doranbri@indigo.ie

Usher Syndrome Study Group (USSG)
c/o Mary Guest
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11 – 13 Clifton Terrace
Finsbury Park
London N4 3SR
UK
Tel: +44 – 20 – 7272 7774
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Email: Mary.Guest@sense.org.uk

Multiply Disabled Visually Impaired European Network
c/o Kent Lundkvist
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Box 9024, S-70009, Orebro
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Tel: +46 – 19 – 6762 151
Fax: +46 – 19 – 6762 210
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C/o Lone Poggioni
Roerkjaersgade 47
DK-6700 Esbjerg
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Siblings Network
Sabine Kersten
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5666GA Geldrop
The Netherlands
Telefax: +31 40 286 38 79
Email: siblingsnetwork@gmx.net
Sabine_Kersten@hotmail.com

The Siblings Network

Sabine Kirsten reports:

I would like to inform you that an e-group was started by members from Spain. Here experiences can be exchanged and questions can be asked by those who

would like to know more about the relationship between deafblind people and their brothers and sisters.

People who are interested in this e-group can contact me for further details. Furthermore, I would like to mention that the DBI European Conference in Slovakia in 2005 will include workshops for siblings as part of the family stream of activities. We believe more siblings will be able to join the workshops this way. There is however still a point of concern and that is funding our network opportunities. This is why I would like to ask each of the organisations present in Slovakia to fund 1 place to enable a sibling to take part in the conference.

For more information I can be contacted by email: siblingsnetwork@gmx.net

EUSN

Marylin Kilsby

The EUSN hasn't arranged any event over the past year. However, we are planning to revamp the organization in 2005 and hold elections. We welcome enquiries from any new members who are interested in joining us.

For more information, please contact:

Secretary: Carol Brill

Email: doranbri@indigo.ie

Acting Treasurer: Marylin Kilsby

Fax: +44 (0)20 7272 3862

Email: marylin.kilsby@sense.org.uk

EdbN

Ursula Heinemann reports:

There are 3 important issues that we are working with at the moment. Deafblindness has been accepted as a unique disability by the European Parliament

This year the members of the European Deafblind Network (EDbN) have achieved a great success, with the adoption of Written Declaration 1/2004 by the European Parliament on 4th April 2004. Following this very important success EDbN wants to be able to work with their member organisations to enable them to really take advantage in their individual countries of this success. In addition,

EdbN wants to enable them to get involved in the European policy making process and the work of the possible UN Convention of the Rights of Disabled People.

In order to move this work forward we made an application to the European Commission. Unfortunately, this time, the application was not accepted, but we will try again. However, we intend to do as much of this work as we can while still seeking funding.

Our principle idea is to organise a number of small training seminars in different parts of Europe and to bring together deafblind people and professionals/family members from three or four different countries. Each seminar would include briefing and training in how to get involved in European policy making and how to use the Declaration to improve the situation in their own country. Deafblind people would be directly involved in each seminar.

Fortunately, the European Deafblind Network has an email network and a website already set up. At the moment these are used to share information amongst the members of the network and inform the public about the needs of deafblind people.

2. Guidelines

After the successful adoption of the Written Declaration, Lucy Drescher from Sense sent out guidelines on how to use the Written Declaration to try and bring about change in individual European countries.

Lucy also went to the Dbl Acquired Deafblind Network Conference in Harrogate, UK. She ran a workshop to explain the guidance and discuss with participants the challenges they face in their individual countries. She also talked about how we can all continue to work together effectively at the EU level in the future.

3. Hearing of the European Parliament

EDbN's next step is to draw up a proposal to request a hearing of the European Parliament about deafblindness. This would be a great opportunity to present a picture of the lives of deafblind people in all the member states and would involve experts and deafblind people from different countries describing their experiences.

Before we can do this we need to put together some information on the situation of deafblind people in each Member State. Lucy and Ricard Lopez have sent out questionnaires to people in each member state and the results will be put together in a report, which will be used to support our request for a hearing.

Contact: talking3@teleline.es

International Network of Parents and Families of deafblind people

Background: Reasons to work in Networks of parents and families:

- Our identity as parents and families of deafblind people. We feel the need to work for the present and the future of our sons and daughters.
- The families with deafblind children (especially those congenitally deafblind or with added impairments) have leadership and representation problems.
- The professionals have organizations and activities to represent them.
- A number of persons with deafblindness and the capacity for self-representation have, or are establishing, organizations and activities of their own.
- The only ones left out are we, the parents and families, together with our children, without the capacity of self-representation. It is necessary to recognise that this situation must change.

The proposal: To set up a network with the aims of:

- Sharing information.
- Coordinating activities and lobbying.
- Training parent leaders to have the capacity to cooperate with the professionals and to follow up on the implementation of programs.
- Cooperating with Dbl and EDbN. It is important that both Dbl and EDbN can dedicate part of their efforts in designing programs for families and that parents are present in all conferences and our voices can be heard.
- Having the capacity for self-representation.

The Steps.

- 1 13th Dbl World Conference, Canada – August 2003. Submission and approval of the Network with the name of “US”. Officially presented to the Dbl as a new Network.
- 2 Dbl Management Meeting and Council Meeting, The Netherlands - February 2004. Confirmation of involvement as a Dbl Network.
- 3 February 2004 – Creation of an electronic group on the internet with the name of IFDbN. The official languages are English and Spanish.

What we need.

We are looking for people who are interested in working from a families' point-of-view. We need parents and representatives of deafblind people, professionals, and people with deafblindness who are willing to act as contact people. The aims of the Network are to:

- Support parents who are involved in working with people with deafblindness, professionals and volunteers;
- To facilitate the exchange of ideas and experiences;
- To initiate projects of common interest; and
- To develop new knowledge through international co-operation.

You can sign up to this network by asking for a form. No entrance or membership fees are needed, only that you are in sympathy with, and will work for, the aims of the Network.

Ricard López
Catalonia & Spain
email: talking3@teleline.es

CHARGE Network

David Brown reports

This has been a very eventful year for anyone involved with people with CHARGE Syndrome, and I have so many things to report that it seems best to list them :

- Perhaps the biggest news is that a group of researchers at the University Medical Centre of Nijmegen in the Netherlands have, for the first time, discovered a CHARGE gene. Informative articles about this can be found in the Fall 2004 issue of CHARGE Accounts, the newsletter of the CHARGE Syndrome Foundation.
- The edition of the American Journal of Medical Genetics that has a special focus on CHARGE is expected to be published in December 2004. It will include approximately 20 articles on medical, genetic, educational, and behavioural aspects of the condition.
- Since August there have been CHARGE Conferences held in Canada, France, and Australia.

Dr Conny van Ravenswaaij came from Nijmegen to attend the latter, and impressed everybody with her insights and humour and warmth. I predict that she will be in great demand at CHARGE events in the future.

- Dr Kim Blake is currently completing a survey concerned with the incidence of osteoporosis in people with CHARGE. Dr Blake reports that every person with CHARGE surveyed so far has had osteoporosis. To take part in the survey contact Dr Blake at Kblake@dal.ca or her assistant at jocelyn.jaques@iwk.nshealth.ca

- Planning is well underway for two important 2005 meetings. The next CHARGE Syndrome Foundation Conference will be in Miami, Florida on July 22nd-24th, details to be found at www.chargesyndrome.org

There will be a meeting of the Dbl Charge Network at the next Dbl European Conference to be held in Presov, Slovakia on August 2nd-7th. Anyone wishing to participate or contribute should contact Joff McGill at joff.mcgill@sense.org.uk

- Finally, a reminder that the Dbl CHARGE Network Listserv is the main point of contact for this network and can be subscribed to at <http://groups.yahoo.com/group/CHARGEnetwork/>

If you have any problems subscribing please contact me at dmbrown1@pacbell.net

David Brown
Education Specialist
California Deaf-Blind Services

Usher Syndrome Study Group

The meeting of the 6th Dbl European Conference in Presov in August 2005 gives us an opportunity to hold an Usher Study Group straight after the main conference.

Bente Heilesen from Denmark and Mary Guest from the UK are hoping to run an Usher Study Group at the same conference venue in Presov on Monday 7th August to Tuesday 8th August.

Themes are yet to be decided. One idea is to include some sessions on the impact of new genetic research on families with Usher. We could also include sessions on lifestyle, work experience, arts/leisure activities. Bente and Mary would like to hear from you about your ideas for a theme, topics for papers and most importantly if you plan to attend.

As is our practice the numbers will be kept to 30-35 to ensure that we can study together easily and get to know one another.

Please send your ideas to:
Bente Heilesen: dbc.behe@nja.dk
and to:
mary.guest@sense.org.uk

The Nordic Cultural Network

Lone Poggioni reports:

“Listen to Me – 2”

The second “Listen to Me“- Family Conference was held in Denmark during 20 – 27 June 2004. More than 70 deafblind, parents, siblings and assistants, from 12 nations in Europe, took part. I have received many e-mails since the conference from parents, saying that the event was well organised and that the program was very varied and interesting, so I think we can say that the conference was a great success. The facilities in Skovhuset – which is an activity center for deafblind adults – were especially admired. The visit to the Deafblind Center in Aalborg was stimulating, inspirational and, last but not least, very instructive for the participants. As Maro from Cyprus said, “this place is the dream for us“. We want to do everything to make this dream to come true.

The presentation of Mr. Lex Grandía was very interesting because its subject has been taboo till now – the sexuality of deafblind people.

Another very important part of the conference was the information about the establishment and purpose of a European organization for parents. Richard Lopéz from Catalonia has, with great effort, ensured that meetings like this have purpose and are very important for all participants.

I am very happy to inform you that the tradition of the “Listen to Me” meetings will continue, in the heart of Catalonia, in Barcelona in 2006.

Listen to US!!...

Peter Fařung from Slovakia responds to the holiday in Denmark this summer.

When we got wind of the information that we would be able to participate in a second family conference "Listen to me 2", we were more than happy! Our pleasure was made even greater because our younger daughter Zuzka, who is not deafblind, could participate too and we could go as a family. We decided to travel together with our Czech friends by car and although the trip was quite long it went all right. When we came to Slettestrande there was a beautiful scene waiting for us – the holiday centre for disabled people. There was everything we could imagine that disabled people would ever need to have a proper rest. We admired the facilities in Slovhuset and especially the centre for deafblind people in Aalborg. The chance to look around these centres was, for us, stimulating, inspirational and last but not least very instructive. We found out that we have a lot to do in Slovakia to be able to provide similar conditions for our deafblind people that would meet Danish standards! What we heard and saw, we will also definitely apply in Slovakia. As Maro from Cyprus said "This is the dream for us" We want to do everything to make this dream to come true.

The presentation of Mr. L. Grandía we found very interesting because it was about a taboo topic – sexuality of deafblind people. We found out that there are many topics about deafblindness which are necessary to solve. Every country has a different priority (integration, education, assisted living, group homes etc...), but what everyone has in common is to help the deafblind to improve their lives. And that is what we all are aiming for.

A very important point of the conference was the information about the establishment and purpose of a european organization of parents. I would like to thank Ricard Lopéz from Catalonia for his efforts in getting this moving forward. It is very important to prepare good conditions for deafblind people internationally and it should be announced in every country that such an organization exists.

The programme of the conference was very varied and interesting so we enjoyed it very much. However, the most emotional experience for me was the donation of a special wheelchair for Dimitrij from Russia. We were rewarded when his great pleasure was evident and he smiled when he took his seat and started to explore its possibilities! We are convinced that this wheelchair will be really useful!

We were all unanimous in our view that meetings like this have a real purpose and are very important for all participants.

To conclude, I would like to thank the organizers for creating such lovely experiences and to Mr.Green and Mr. Lolli for supporting us. We were very happy for the whole week. THANK YOU!!!

PS. We are glad that the tradition of the meetings will continue with the next one taking place in the heart of Catalonia, in Barcelona!

European Family Conference 2006

LISTEN TO ME .. 3

EDbN Announcement and call for papers and proposals

The 5th European Family Conference will be held in Barcelona, Catalonia, Spain, before or after the summer of 2006. The previous family conferences have been held in Slovakia, The Netherlands, Italy and Denmark. Since Italy this event has received the name of "Listen to me", so the Barcelona event will be called "Listen to me 3".

Catalonia

Barcelona has a very important international airport and there is a second international airport in Gerona. There are various cheap airline companies which operate to and from these airports. Barcelona is an important tourist site and Gaudí, Dalí and Picasso are some of the well-known Catalan artists.

In Catalonia the beaches are splendid and there are many tourist sites ideal for family holidays.

This conference will welcome a number of professionals, especially from countries without family representation, supporting family members or from family organizations.

Conference Themes

The organisers of the conference are interested in having two specific focus areas:

- 1 IFDbN – the International Parents and Families Network.
- 2 The Siblings Network – so there are some siblings in the organizing committee.

EDbN Conference organisers are requesting papers and proposals for activities, including seminars or pre- or post-conference programs.

Sponsorship

EDbN Conference organizers are requesting sponsorship assistance from individuals, corporations, governmental and non-governmental organizations, philanthropic associations etc. Sponsorship assistance can be in the form of direct financial donations or the purchase of various conference fixed cost items.

- Financial donations can be used to offset the registration and accommodation fees for deafblind families, intervenors and interpreters attending the conference etc.
- Purchase of conference fixed cost items can include: conference luncheons, dinners and coffee breaks; conference AV; transportation costs; costs of special communications for persons with deafblindness; thank you gifts for all participants etc.

To request more information on the Conference, and to be included on the mailing list, contact:

Ricard López

Telephone: +34 93305 4385

Fax: +3493331 4220

Sms: +34 678 712 619

E-mail: talking3@teleline.es

French CHARGE Conference

POITIERS, 17-19 September 2004

Since 1996, the French Association of Parents of CHARGE children (Association CHARGE) and CRESAM have joined together to organise a bi-annual conference on CHARGE. The purpose of these events is to inform families and professionals about the state of the art concerning CHARGE.

For the 2004 conference, CRESAM and the CHARGE Association felt that more ambitious plans could be made and decided to set up a stronger planning committee of family representatives, a medical expert and CRESAM professionals.

The preparation of the program tried to take into account the changes in the expectations of the families that have taken place over recent years. 10 years ago, families were mainly interested in the medical treatment of their children and their survival. Now, they have more questions about behaviour, education and development. This new interest led the CHARGE Association and CRESAM to set up a research project based on a questionnaire on behaviour which involved families of France, UK, Italy and Spain. In the same way, several conferences

(European CAUSE Conference in UK 2003 and the American Conference in Cleveland in 2003) put this question on their agenda.

The final 3-day program covered the following areas:

- General presentation of the syndrome
- Genetic aspects
- Early intervention
- Multi-sensory approach to development
- Vision
- Endocrinology and puberty
- Feeding and olfaction
- Cognitive development
- Behaviour and communication

Another novelty was to provide the opportunity for the families to come to the conference with their children, which meant organising activities for CHARGE children and also siblings.

So, on the 17th September 2004, a huge gathering took place in a University campus near Poitiers. There were 74 family members, 26 children with CHARGE and one adult with CHARGE, 69 professionals, 4 siblings and 10 lecturers.

The families very much appreciated the general organisation of the conference and the quality of the activities for the children, which allowed them to concentrate on the conference in a relaxed way.

The participants were particularly interested in the following:

1 The latest genetic discoveries, initiated in the Netherlands and followed up in the USA, France and Australia, were addressed by Pr Stanislas Lyonnet and Dr Damien Sanlaville. The parents were very relieved by the fact that CHARGE is a genetic condition which is not present in brothers and sisters.

2 All the questions concerning behavioural problems were approached in a functional and dynamic way by David Brown (Educational specialist in California), Catherine Peigne, Elisabeth Lasserre and Jacques Souriau. The conclusion was that the "strange behaviours" which are often observed in CHARGE children are the result of their sensori-motor conditions and adaptation to their environment.

3 Dr Véronique Abadie, Dr Nathalie Loundon and Dr Graziella Pinto answered questions about feeding, cochlea implants and endocrinology.

This conference provided a nice surprise during the Saturday evening party as, during a show by African percussionists and dancers, all the CHARGE children participated with a joy and a creativity that amazed both parents and professionals. During this 1-hour episode, the children demonstrated their capacity to overcome their motor and sensory limitations. They demonstrated that their unusual behaviours could be extremely functional in a relevant context. All the adults were thrilled by the way the children confirmed the vision that was

promoted during the conference regarding “challenging behaviours”. As David Brown commented, “it was worth travelling from San Francisco to France just for this fabulous evening”.

All the participants are looking forward to repeating this experience. New aspects should also be developed, such as the problems raised by the siblings and the emotional development of children and young adults.

Ideas were also expressed about a possible European project for the families of children with CHARGE.

Contact: Jacques.souriau@cresam.org

Acquired Deafblindness Network holds successful 5th International Seminar

148 delegates from 17 different countries gathered in Harrogate, England between 29 October and 2 November to participate in the 5th International Seminar of ADBN.

ADBN have held such seminars approximately every 2 years since 1994. Each successive event has attracted a larger number of delegates than the one before.

The growth in the importance and popularity of this conference reflects an increasing understanding of the phenomenon of ADB and a corresponding interest in work in this field from social workers, the medical profession and policy makers.

The Co-ordinating group of ADBN are also keen to develop a sense of continuity and progress in this work and chose to link the outputs of the last seminar in Zurich 2002, with the inputs to the event in Harrogate 2004.

The theme of this seminar was “Expectations, Opportunities, Possibilities – exploring the relationship between the people in the world of ADB”. The use of the word “expectations” was deliberate and reflects ADBN’s desire as a network to be more inclusive in their work and to recognise ADB people not as passive users of services but as active consumers with expectations and, crucially, a voice.

As a result of this commitment deafblind people themselves were represented this year more than ever before. Three Plenary sessions and a number of workshops were delivered by people with ADB.

The conference also heard major presentations on the development of legal rights for deafblind people and the benefits of technology in the quest to enable people who are deafblind to take ever more control over their own lives. These were two subjects that the Zurich 2002 seminar called for more attention on.

Evaluation and feedback on the Harrogate conference has been extremely positive. Attention now turns to preparation for the 6th International Seminar of ADBN, which will take place in The Netherlands in Autumn 2006.

Ges Roulstone
Chairperson
ADBN

Australia News

7th National Deafblind Conference

The 7th National Conference was held at Melbourne's Rydge's Boardwalk Hotel from 2-5 July, on the theme "Deafblind and Moving On". 108 people attended the event on its first two days, and 85 people registered for the professional third day. After 12 months of intensive planning, hard work and commitment by the Conference Committee and staff members of Victoria's Deafblind Association, it was widely held to have been a highly successful event.

Appreciative feedback related to the diversity of speakers, support for participants, and well planned mechanisms for dealing with emergency and last-minute requests. It was a rewarding and satisfying time for all involved.

Keynote Speaker, Mark Landrenau from Seattle Lighthouse set the tone for the Conference with his motivating charm and his ability to converse endlessly with many who attended, particularly those in the Australian and New Zealand Deafblind community. Mark, who has Usher Syndrome, is totally deaf and legally blind. He lives in Seattle, Washington, and works as a Government Affairs Specialist for the Seattle Lighthouse for the Blind.

Conference papers can be accessed at www.dba.asn.au

Australian deafblind council wins research grant

The Commonwealth Government's Department of Family and Community Services has invited ADBC to investigate the current needs of, and services for, Australians who are Deafblind and has offered ADBC a substantial grant to undertake a review of the Ward (1994) Report which had initially addressed

those topics. The report had also provided estimates of the incidence of deafblindness nationally.

A project brief is currently being prepared and it is hoped that a project officer might soon be appointed. Accountability reporting requirements are stringent, with Government requiring a monthly submission from ADBC's Executive Officer.

Schooling: new money for literacy and numeracy

The Federal Government has introduced legislation setting out its agenda for Australian schools. The legislation will provide \$31.3 billion for schools and \$2.1 billion for Indigenous education over the next four years. The funding is conditional on the States and Territories and non-government school authorities meeting a number of requirements that will underpin national priorities – greater national consistency in schooling; better reporting to parents; transparency of school performance; greater autonomy to school principals; creating safer schools; common commitment to physical activity; better approaches to boys' education; developing the teaching workforce; making values a core part of schooling; accelerating Indigenous education outcomes; helping families with post-school choices.

Funding of \$4 billion over four years will be allocated to students and schools in need of extra help; of this \$2 billion will be targeted to the education of the most disadvantaged students, with a focus on literacy, numeracy and help for students with disabilities. For more information, visit www.dest.gov.au/ministers/nelson/jun_04/npm_220604.htm.

New Disability Standards for Education

The final draft of the Disability Standards for Education that will affect all Australians, irrespective of disability, was released by the Commonwealth Government on 16 June. The Attorney-General intends to introduce legislation to amend the Disability Discrimination Act, and the Standards will be formulated and tabled as soon as the legislation is passed. The Internet link for the Standards, Guidance Notes and Regulation Impact Statement is http://www.dest.gov.au/research/publications/disability_standards/default.htm

Deafblindness in court

The NSW Law Reform Commission has released a discussion paper (<http://www.lawlink.nsw.gov.au/nswlrc.nsf/pages/refjury>) that examines whether people who are profoundly deaf, or have a significant hearing or sight impairment, should be eligible to serve as jurors and, if so, in what circumstances. Submissions were received until 30 April 2004 and a report is expected in the latter half of 2004.

Ballot dancing?

On 22 April, representatives of Australian Blindness Forum, Blind Citizens Australia, National Disability Advisory Council and Vision Australia Foundation met with Petro Georgiou, Chair of the Joint Standing Committee on Electoral Matters to emphasise the need for electronically assisted voting to be trialed in Federal Elections. While trialing is not possible before the impending Federal Election, submissions asking for electronically assisted voting for people who are blind or vision impaired will be lodged with the Committee Inquiry to be conducted after the Election. The goal is to obtain the Committee's support for recommendations to be made to Parliament that will appropriately amend the Electoral Act 1918.

From New Zealand

In April a Bill was introduced into the NZ Parliament, signaling the first step towards the recognition of NZ Sign Language as the third official language with Maori and English. The immediate effect of the Bill, once passed, will be to provide people with the right to use and access NZ Sign Language in legal proceedings, including in court. Read the media release at <http://www.beehive.govt.nz/ViewDocument.cfm?DocumentID=19399>

Major Merger

Three of Australia's largest Blindness agencies have agreed to unite. The Sydney-based Royal Blind Society of NSW, the Melbourne-based Royal Victorian Institute for the Blind and Melbourne-based Vision Australia Foundation will reorganise under the interim name; RBS/RVIB/VAF Ltd. The new organisation has received letters of support from Retina Australia, Blind Citizens Australia and the Deafblind Association of Victoria. More information is available by phoning the toll free Nexus hotline – 1800 355 335, or by email: nexus@rvib.org.au.

New Training Resource from Western Australia

News flash: "We have Contact!" Training resource now available
"We have contact!" is the third training resource produced by Deafblind Specialist Services of Senses Foundation (formerly West Australian Deafblind Association and Royal WA Institute for Blind). "We have contact!" is a sensitive and respectful approach to interacting effectively with children who are deafblind with other conditions, eg. CHARGE.

A key underlying principle is acknowledging behaviour as communication. Strategies presented are also demonstrated with an adult. All examples are from original Individual Communication Guides (ICG) – videos which demonstrate an individual's personalised communication system. We are hugely grateful to the

families for giving permission to share their personal ICG resource with others. This 27 minute open-captioned video/DVD is available in both PAL and NTSC formats.

Please contact Senses Foundation on reception@senses.asn.au for an order form for this unique resource.

Communication Strategies

Renwick College at North Rocks near Sydney held a five day event (July 7-11) event entitled Communication Strategies for Students with Sensory and Multiple Disabilities, with Sharon Barrey Grassick (Communication Specialist at Senses Foundation of Western Australia) as keynote speaker and conference leader. The event drew 66 participants. A follow-up event on designing and implementing a curriculum, featuring Professor Jan van Dijk, was cancelled due to his ill health.

World Conference 2007

Good news travels fast, so many readers may already know that Senses Foundation has won the bid to host the next Deafblind International World Conference in Western Australia in 2007! Start saving your pennies.

Australian Deafblind Council Office Bearers 2004-6

The ADBC committee consists of Sven Topp, NSW (President), Leah Hobson (WA), (Vice President); Emma Gordon, (SA)., Peter Minter (NSW) representing people with deafblindness, Gail Staggs (QLD), parent representative; Cloan Makgill, New Zealand, and three other members – Mike Steer (NSW), Sharon Barrey Grassick (WA)(Secretary), and Celestine Hare (VIC) as Legal Officer & Treasurer.

USA

Sculpture of Helen Keller

A bust of Helen Keller was recently made by Daniel Altshuler, U.S. Sculptor, and may be view at:

www.arborgate.net/helenkeller.jpg

www.arborgate.net/helenkeller2.jpg

The 3/4 life size bust of Helen Keller may be seen in the clay model on the special web pages listed above. We will have photographs soon of the bronze cast mounted on a wood base with a brass plate in Braille (with her name, dates

and “I am not dumb now.”) This bust was made so that blind people can see who Helen Keller was by touch. Seeing persons can also appreciate the bust.

The Helen Keller bronze bust will be on exhibition at the Perkins School for the Blind this November during their major event.

If you are interested in purchasing a bronze cast of this bust, please e-mail me at the address below.

Contact : William Hackney on wmhackney@earthlink.net

Laos

Can you offer support to this new association?

We are from the Laos Deafblind Association, which has just been established in the Laos P.D.R in South East Asia. We are a not-for-profit organization with the purpose of helping deafblind people in Laos to work for themselves and live a normal life as much as they can. Because our organization is a new NGO we currently have a problem with getting funding to support our activities and projects. Right now most of our funds are from local donors, which means they are very limited.

On the Internet we found that you and your organization have a very long and strong experience in managing a global organization, which has network connections across the world. So we would like to request advice and help from you and your member organizations in managing our project, developing activities and finding support.

So, if you have any advice or information that could help us please feel free to write to us at any time. We would appreciate it!

You can contact me at this e-mail address: laoblind@yahoo.com

Thank you
Khouanetyphong. D

East Africa

Penny May Kamau reports:

The sixth regional meeting for educators of the deafblind took place in Kisumu, Kenya from 7th to 9th June 2004. The meeting brought together teachers, Headteachers and District Education Officers from the ten school programmes for the deafblind in the East Africa region. Also participating were parents, and officials from Ministries of Education and Social Services. The aim of the meeting

was to review the school programmes and to make new work plans for the coming year.

From reports presented by the school programmes, there were a number of key issues that arose, these included, for example, need for training in family counselling.

Access to counselling

Many deafblind children are now being identified and teachers are finding themselves increasingly taking on the role of counsellor in many situations. Specialised counselling services are not widely available in East Africa but it is an area that needs urgent attention.

Free Primary Education

The access to free primary education also generated a lot of discussions. Kenya has recently implemented a policy of free primary education but for deafblind children the options are few. Specialised services cannot be provided in every local primary school and in most cases residential school is the only option (all deafblind programmes except one are attached to residential schools for the deaf) and with this there are cost implications.

During the discussions the Ministry of Education was challenged to look into this issue and see to it that deafblind children also get access to free education.

Teacher supply

In Uganda and Tanzania the lack of teachers was a major issue, this is mainly due to the increase in the number of deafblind pupils who are being identified and lack of funds to employ more teachers.

In Uganda there is also no special policy on teacher pupil ratio for deafblind pupils and this needs to be addressed. Ministries in both countries have promised to post more teachers where possible

Congratulations Kenya!

In Kenya the situation is much better as the ministry of education have ensured that programmes for the deafblind are well staffed. The teacher pupil ratio in Kenya is one teacher to two pupils or in some cases one to one, the Ministry needs to be congratulated for this!

Vocational Training

Another theme for this meeting was vocational training and transition, and on the second day of the meeting all participants visited Sikri Vocational Training Centre where deafblind students learn alongside blind and deaf students.

After a tour of the centre to see at first hand the training offered, participants had the opportunity for further discussions touching on training and transition to adult life.

The Association of Swedish Deafblind (FSDB) in co-operation with the Christoffel Blinden Mission (CBM) have been working to develop services for the deafblind in East Africa since 1985. In 1997 FSDB employed a rehabilitation officer, who has been working to develop a model for transition and support to deafblind persons who have completed their training. This model which has been developed entirely from the African perspective, is community based and aims at preparing the deafblind person, their families and respective communities. In the best possible way in order to give the best quality of life for all.

Participation from the Ministry and a conference in 2005

During the meeting the official from the Ministry of Social Service took a very active role in the discussions, and it is hoped that government can take over more responsibility for these services in the future. In order to carry this process a step further, FSDB will host a conference in co-operation with CBM and the Ministry of Social Services early next year which will focus on rehabilitation services for deafblind persons.

Sweden

Mullsjö 2004 – A holiday to remember!

Colin Bennett had a time to remember when he joined the European Deafblind Holiday when it was hosted by the Association of the Swedish Deafblind in southern Sweden last summer. Colin really enjoys meeting people and seems to relish the perils of travelling alone in new places. This article is like reading his diary, as, with plenty of personal asides, he recounts his adventures across Europe

...

I felt all the old thrill of travelling as I waited at Victoria Coach Station in London for the bus to Amsterdam in the Netherlands. It was late June 2004 and I was going to the annual European Deafblind Holiday, organised this year by the Association of the Swedish Deafblind (FSDB), to be held at Mullsjö in southern

Sweden. It was to be held between 5-11 July, so why was I so early and why was I going by bus and via Amsterdam?

Well, I had a free return ticket to that city (why? is another story!) and as I intended to spend some time in Scandinavia and Finland I decided to buy a "Scanrail" run-around ticket, valid for any ten days in those countries in July and August. As an "ancient" person, it cost me £207 which is cheap, considering I travelled over 5,000 km on fast comfortable trains and ferry boats.

We travelled through the night to Amsterdam, where I had hoped to catch a fast bus along the coast to Friesland. However, I couldn't find such a bus so I headed for the Central Railway Station where I got lost due to the massive rebuilding work there. Two friendly traffic cops rescued me and I took a train to Leeuwarden. I managed to find a B and B in a private house and had an enjoyable night there. I took other trains to Germany, meeting interesting people on the way, and caught a train from Hamburg up the eastern side of Denmark. My ticket took me to Puttgarden where my Scanrail ticket began. However, I had taken the wrong train and found myself heading towards the western side of Denmark. These things happen if you can't see a lot! The ticket inspector didn't make a fuss. There was a very interesting woman in my carriage who was a radio presenter going home to Flensburg. I had to find a place to stay before nightfall – when I can see nothing. She used her mobile phone to talk to her mother and they thought I should get off at Frederice. Well, I had some difficulties there but ended up spending the night in the Seamen's Home. It was very nice and I had a wonderful five-course breakfast.

I was on the "wrong" side of Denmark but I made the most of it and eventually reached Sweden after many adventures, all of them enjoyable, except perhaps the night I had to spend outside the main station in Malmö. (Buy me a drink (or two) when you see me next and I'll tell you all about them.)

Anyway, I arrived at Mullsjö in the rain and found the Folk High School where the holiday was to be held. I was the first to arrive but Mia, the jolly FSDB organiser, arrived from Stockholm and we found our rooms which were in pleasant student blocks. I shared my room with Jan Jakes, the co-ordinator of European Deafblind Holidays. He made a very good impression on me as he does everyone. We also met Gunilla, the cook. My father, an old soldier, taught me "Always make friends with the cook" and I do. For the next week we all had wonderful food: I still dream about it.

On the Monday, all the participants were there: about 45 deafblind people and 75 communicator/guides and other helpers. I have to say that I enjoyed every minute and I think we all did. Besides Mia, there were local lads Peter and Leif, ably assisted by Ingemar and Thorbjörn. The organisation was fine and well-balanced between trips and free time. It happened to be the wettest summer in southern Sweden for decades but that didn't bother us. Sunstroke is not a

common cause of death in Sweden and we lost no-one to that cause – although perhaps there was some foot-rot!

The wettest day was the one when we went to the island of Visingsö in Sweden's second largest lake, Lake Vättern. We had planned to visit the famous herb garden there and the Brahe Church. We couldn't do that but we did visit Visingsborg Castle and we had a slap-up meal at the local restaurant. The speciality was a fish called "sik". I'm sure that sounds better in Swedish.

Other outings were to a local sweet/candy factory, a splendid "canothing" (Leif's word for canoeing – I like it !) and a ride on magnificent horses. I disgraced myself by falling off mine. (Mind you, mine was an "unbroken" wild stallion and I had no saddle or bridle – well, that's my version, anyway).

We had useful general planning/discussion meetings every day and a full social programme every evening.

Very successful was the international indoor sports and quiz competition that we non-Swedes gracefully allowed the contingent from the Swedish Youth DBU to win. On Saturday there was a great disco dance with excellent food. The music was...er... er..."interesting" in style and standard. Sadly, most of us went home on Sunday but I'm sure many of us had made lasting friendships.

However, I left on Monday for a big trip starting with the journey to Stockholm and then an 18-hour 1300+ km rail journey to Kiruna in the far North. I then spent time in Finland, visiting the farms where I had worked 40 years ago (I had a whale of a time) and then home by train, bus and ship to Calais and then over the Channel. That's a big story! I was away a month.

Colin Bennett
Hove, Sussex, UK

colinbbennett@onetel.com

In any communication please use black font if you can!

Scotland
Voyager Princess – an amazing and moving production

Expressions Unlimited brought together deafblind and non-disabled artists from Italy, Croatia, Slovakia, Scotland and Greece and the work was professionally staged in Glasgow, Scotland this Autumn. Our theatre critic reports:

The auditorium was in darkness as we made our way to our seats. Once inside and settled we could see and feel the atmosphere. Beyond us on the stage was a tall ship with magnificent sails. Already it felt as though we were looking through a spyglass, back in time, across a beautiful sea and into the past.

The operatic drama "Voyager Princess" was superbly produced and directed with the entire cast giving utterly convincing performances. The lead young lovers were entirely believable in their devotion and the supporting roles from Captain and crew, elegant and studied. The Cabin Boy was perfect.

The setting and all the special effects made it possible for the cast and audience to experience the excitement and pathos of the story – which the cast and ensemble had written and developed together over a series of meetings supported by the EU.

A brief history of Dbl

Michael Collins, from Perkins School for the Blind and Immediate Past President of Dbl, prepared this for our Council meeting of November, 2003. It is a historical summary of the evolution of Dbl, for the orientation of new members. Most of the dates and facts are substantiated by record or discussion with long-term members. However, it is possible that there are still some errors in this record. We would appreciate your feedback and corrections, so that the record may be corrected.

Pre-Constitution Era

The pre-Constitution era in the story of Dbl is what I would refer to as the infancy of our organization. The roots of our organization go back to the 1950s, when just a few organizations around the world were beginning to collaborate. Among this group were organizations and schools such as Condover Hall in the U.K., the school for the blind in Hannover, Germany, the Institute for Defectology in Moscow, Michielsgestel in the Netherlands and Perkins Schools for the Blind in the USA and several schools from the Nordic countries. This group corresponded by mail, sharing the results, successes and frustrations of their work with deafblind children and, on rare occasions, managing to visit each other.

It was in 1962 that this group first met for a formal conference, "Teaching Deaf-Blind Children", hosted by Condover Hall School near Shrewsbury in the UK. 41 people attended this first conference. Subsequent worldwide meetings were held during the '60s in the Aarlborg School in Denmark, and at St. Michielsgestel in the Netherlands. During this era, nearly all the membership in attendance was concerned with the education of children who are deafblind, and thus the emphasis on "education" in the title of the organization.

During the '70s, world conferences were next hosted by Perkins School for the Blind in the USA, by Condover Hall once again, and then in Sydney by the Australian schools serving deafblind children. During the early part of this decade, the group met officially as a Sub-committee, on the Education of the Deaf-Blind, of the larger mother organization known as the International Council for the Education of the Visually Handicapped (today known as ICEVI). Attendance at conferences was in the 100-200 range. Many more organizations began to attend meetings, especially from Europe and North America.

It was during the Sydney conference in 1976 that the International Association for the Education of the Deafblind was officially born, electing Keith Watkins of Australia as its first Chairman. Membership was strictly individual, at a cost of about \$10 per year, which most members prepaid for four years at the world meetings. Due to the limited revenue of the organization, the IAEDB had a very small, mimeographed newsletter of about eight pages. There was literally no budget for any other activities, so right up through the '70s the only activities were the world conferences every three or four years.

The first world conference during the 1980s was hosted by our German colleagues at the Bildungszentrum fur Taubblinde in Hanover. This meeting I remember vividly, since it was my first exposure to an international professional environment. I remember clearly the sense of awe and delight I felt at being in a week-long meeting in which all of us, from the corners of the globe, understood each other and spoke the same professional language, since we were all concerned with the education of children who are deafblind. This conference was early enough that most of the Founding Fathers of our field were still very much in attendance, and influencing future directions of the organization. The organization was still very Euro-centric and North American. It is important to remember that not very many participants were coming from developing countries. It is estimated that, in this era, fewer than 250 deafblind children were being served in 11 developing countries, worldwide. A few of these members managed to attend the very next world conference in New York City, in 1984, which was hosted by the New York Institute for the Blind.

The Constitution Era

It was during the world conference held in Poitiers, France, in 1987, that the obvious rapid growth of our organization prompted us to more fully develop and

establish a constitution under which we could function in the future. A committee was appointed for this purpose. Bryndis Viglundsdottir of Iceland, with assistance from Rodney Clark of the UK, our Secretary at the time, drafted a constitution which was presented to our Executive Committee and approved in Madrid in 1997, later to be ratified at our world meeting in Cordoba, Argentina in 1999.

A few significant changes in the makeup and focus of our organization came about as a result of the Constitution. It was decided that IAEDB would no longer have a sole focus on education, but that we would concern ourselves with service delivery to the full spectrum of deafblind people, from infancy through adulthood. It was consequently determined that members need not be only teachers concerned with education, but may also be a great variety of people interested in deafblind services, including, but not limited to, administrators, clinical specialists, family members, rehabilitation and adult services workers, and deafblind people themselves. This decision has resulted in the rapid expansion of membership and a great growth in the scope of topics covered within our meetings and conferences.

It was similarly determined during the 1980's that IAEDB must begin to take steps to expand itself into a truly worldwide organization, by encouraging development of services and participation of members from the developing world, especially in Asia, Africa, the Caribbean, Latin America and Eastern Europe. Over the next few years, international efforts were founded within organizations such as the Swedish Federation of the Deafblind, Christoffel-Blindenmission, the Hilton/Perkins Program and Sense International. The support of such organizations resulted in significant expanded participation from all corners of the world, beginning with the world conference in Orebro, Sweden, in 1991, and continuing through the present day.

The Deafblind International Era

It was from 1996 to 1999, during the Presidency of Marjaana Suosalmi, that our organization took on its current configuration. She appointed a Strategic Planning Task Force, comprised of several leaders of the field, who studied the nature of the organization and recommended several changes in our structure. The recommendations of the task force were presented for the ratification of the membership at the world meeting in Lisbon, Portugal, in 1999. Many important changes resulted from this reorganization. The IAEDB was reborn as Deafblind International, a name which the membership felt more accurately represents the array of issues and services we represent in the current era. We reinvented the organizational structure of the association, recognizing that we are essentially an organization with a strong network sub-structure, in which people of common interests meet and interact more frequently between conferences. We established a new governance structure, in which the former Executive Committee was dissolved and a Council and a Management Committee was put in its place. We established a dues structure for small and large corporate

members, resulting in greatly increased income for our organization. This increased revenue has resulted in a much greater array of activities and efforts that we can support, including a modern, state-of-the-art magazine and web page.

Today, Dbl represents programs and services for thousands of deafblind people around the globe. We have evolved into a mature, broadbased professional organization. During the '80s we were able to initiate regional conferences in Europe, the first of which was held in Brugge in 1986. Five of these have been held to date, with participation having increased from about 300 to now over 500 attendees. We held our first Asian conference in Ahmedabad, in 2000, in conjunction with a regional conference of ICEVI. The next of these will occur in Nepal, in 2004, and others are expected in other developing regions of the world in the future. Several of our networks now hold their own smaller meetings and conferences on topical themes, and some of these have as many as 200 attendees. Our membership now includes professionally active persons from places as diverse as Cuba, Tanzania, Indonesia, Nepal, China and the Ukraine. The growth and expansion of our organization in the coming decades is limited only by the limits of our imagination.

Deafblind International Conferences

World Conferences Attendance

1962	Condover Hall, Shrewsbury, UK	41
1965	Kalundborg, Denmark	62
1968	Sint Michielsgestel, Netherlands	
1971	Perkins School, Boston, USA	
1974	Condover Hall, Shrewsbury, UK	112
1976	Sydney, Australia	230
1980	Hannover, Germany	176
1984	New York, USA	
1987	Poitiers, France	400
1991	Orebro, Sweden	450
1995	Cordoba, Argentina	350
1999	Lisbon, Portugal	652
2003	Toronto, Canada	555

Regional Conferences

1986	Brugge, Belgium	
1989	Warwick, UK	380
1993	Potsdam, Germany	370
1997	Madrid, Spain	420
2000	Ahmedabad, India	300+
2001	Noordwijkerhout, Netherlands	530

1st International Virtual Congress on Deafblindness in Spanish

Dates: 1st April to 31st May 2004

Organization:

Organized by APASCIDE (Spanish Association of Parents of Deafblind Persons); APSOCECAT (Catalan Association of Parents of Deafblind Persons); Hilton Perkins (Latin America); Sense International (Latin America) and the Spanish World Forum on Deafblindness under the honour presidency of HHMM Sofia, Queen of Spain.

Some numbers

There were more than 600 subscriptions from schools and training centres all over the world, with a single subscription for all its professionals.

90 high quality papers in Spanish from many countries were displayed in 9 virtual classrooms.

Technological platform of the congress

The congress was hosted by the UOC (Open University of Catalonia – www.uoc.edu) under the program “Campus for Peace” on development and volunteers. The UOC has 30,000 “virtual” students and the platform is validated for individuals with visual impairments.

Conclusions and evaluation

This is the first virtual congress on the topic of deafblindness. The low level of people’s knowledge of computers and the internet was a handicap, and the UOC worked hard on individual support and technical help.

A resulting benefit of the congress is the translation, into a Spanish edition, of the excellent CD-Rom “Child-Guided Strategies for Assessing Children Who Are Deafblind or Have Multiple Disabilities” by Dr. Jan Van Dijk and Catherine Nelson.

From the scientific point of view, some papers achieved an honourable mention for their discovery and innovation in “social research”, “evaluation methods”

amongst other things. The quantity and quality of the papers caught the imagination of the Spanish deafblind world.

This success was achieved thanks to Spanish being the official language (English is a barrier for us) and the virtual modality (time and money is other barrier).

A virtual congress may seem distant and unfeeling because of the loss of human relationships, but the “chat” function of the Campus allowed everybody to be in contact with each other.

The evaluations indicate that everybody has the intention to take part in the next virtual congress.

Ricard López

1st International Virtual Congress on Deafblindness in Spanish

e-mail: talking3@teleline.es

Helen Keller International Award exhibits in Glasgow

Art competition about deafblindness to showcase entries at Collins Gallery

The Helen Keller International Award returns to Glasgow, exhibiting at the Collins Gallery Glasgow, from 8 January until 12 February 2005. With over 170 entries received, the contest for the trophy and £1000 prize should be strong and it is down to a group of judges to decide on the shortlist and winner. Judging takes place at the start of the exhibition’s 5 week run, giving visitors a chance to discover if their favourite is among the 6 shortlisted works. The winner is announced at an awards ceremony in the gallery on January 31st.

Run by Sense Scotland since 1992, the competition is open to any artist, with the only criterion being that work submitted must be on the subject of deafblindness. Sense Scotland supports children and adults who face challenges every day of their lives due to deafblindness, sensory impairment, physical or learning disability. The award’s international status is a huge part of its success.

“With entries from across the UK and country’s including Switzerland, Serbia and Montenegro, Hungary, Russia, USA, Israel and Germany, the Helen Keller International Award demonstrates a worldwide understanding of deafblindness,” explains Gillian Morbey, Chief Executive at Sense Scotland. “The competition’s success also highlights the importance of art as a vehicle for communication and self-expression. I know from past shows that the diversity and quality of work make this a fantastic exhibition.”

Venue:

Collins Gallery, University of Strathclyde, 22 Richmond Street, Glasgow G1 1XQ

Dates: 8 January to 12 February 2005

Telephone: 0141 548 2558

Opening hours:

Mon-Fri 10am-5pm Sat 12noon-4pm Sundays-Closed

Free entry. Wheelchair entry on Richmond Street. NCP car park off Montrose Street.

For more information about the Helen Keller International Award or the Sense Scotland arts programme, contact:

Lindsay Mitchell, Arts Manager Mobile: 07974 943898

Email: arts@sensescotland.org.uk

Web: www.sensescotland.org.uk/helenkeller

For information contact Graeme Thomson, Communications Officer:

Email: gthomson@sensescotland.org.uk

'We have contact!'

'We have contact!' is the third training resource produced by Senses Foundation (formerly West Australian Deafblind Association and Royal WA Institute for Blind). 'We have contact!' is a sensitive and respectful approach to interacting effectively with children who are deafblind with other conditions, eg. CHARGE.

A key underlying principle is acknowledging behaviour as communication. Strategies presented are also demonstrated with an adult. All examples are from original Individual Communication Guides (ICG) – videos which demonstrate an individual's personalised communication system. We are hugely grateful to the families for giving permission to share their personal ICG resource with others.

This 27 minute open-captioned video/DVD is available in both PAL and NTSC formats.

Please contact Senses Foundation on: reception@senses.asn.au for an order form.

Dbl Awards 2005

Nominations are being sought for the Dbl Distinguished Service Award to be presented at the Dbl European Conference in Slovakia in August 2005.

The Distinguished Service Award is presented to people who have significantly contributed to the deafblind field, or Dbl, internationally. These awards are presented at any Regional or World Conference. Since 1987 there have been 18 winners of this award.

Nominations

The Management Committee has appointed Bernadette Kappen and Anny Koppen to be the Awards Committee. All communication on this subject should be sent to them via email:

Bernadette Kappen: bmk@obs.org

Anny Koppen: anny.koppen@statped.no

The deadline for nominations is 31st March 2005.

To nominate someone please submit a brief summary giving details of who you are nominating and why. You must also attach a biography of that person. This information must be sent to Bernadette and Anny by 28th February 2005 at the latest.

Network Co-ordinators required!

Dbl's most important way of communicating its ideas and generating new ones is through its networking capacity. The Networks are able to bring members together from around the world so they can share their interests with each other and, at the same time, feel professionally supported through this type of contact.

At the moment we have two Networks that are in need of a new co-ordinator to provide a focus for members who are interested in developing their ideas in these areas!

Staff Development and Employment

Both staff development and employment are really significant for Dbl membership and there is a lot of interest out there. If you are a member already or you have an interest and a little time to spare we would invite you to volunteer your services.

Please get in touch with Anny Koppen – thank you!

“Our right to be deafblind with full participation in society”

Tampere, Finland June 3-7, 2005

The Finnish Deafblind Association, together with the World Federation of the Deafblind, will arrange the 8th Helen Keller World Conference and the 2nd General Assembly of the WFDB at Tampere in June 3-7, 2005.

Hundreds of deafblind people from all around the world will gather together at Tampere to share experiences and information. Professionals working within the field of deafblindness will meet and examine the latest innovations. The conference theme will be manifested in many sessions, workshops and exhibitions at Tampere Hall. The diversity of deafblindness will be celebrated in special occasions during the conference. There will be discussions about the rights of deafblind people to, eg communication, information, education, employment and self-expression.

Official language

The official language of the conference is English. There will be interpretation in International Sign.

Registration fees by 31.3.2005/after 31.3.2005

Deafblind participants, their interpreters, guides, assistants or family members per person 200€/250€

Professionals 250€/300€

One-day registration 125€/150€ (available for Friday, Saturday or Sunday)

Registration fee will include the conference programme, daily lunch and two daily coffees/teas.

Also the Evening Programme is included in registration fee. The Evening Programme consists of

Get-Together Party on June 2nd, Tampere City Reception on June 3rd and the Finnish Evening on the Viikinsaari Island on June 6th. During the conference there will also be art exhibitions of and for deafblind people to sense and experience at the Tampere Hall.

Accommodation

It is possible to make reservation for accommodation in the registration form. Registration will begin in November-December 2004. Tampere Conference Bureau will assist participants with registration and accommodation. Special rates are available for conference participants at several Tampere hotels.

Price for a single room for one night (including breakfast) will vary from €55 to €105 and price for a double room from €55 to €109. Most of the hotels are located within a walking distance from the conference venue, Tampere Hall. Information about the largest conference venue in the Nordic countries is available at: www.tampere-talo.fi/english.

More information about the 8th Helen Keller World Conference, also abstract proposals and applications for travel subsidies:

Päivi Rissanen, Project Co-ordinator
P.O. Box 40, 00030 IIRIS, Finland
tel. +358-40-753 2026, fax: +358-9-5495 3517
e-mail: paivi.rissanen@kuurosokeat.fi
www.helenkeller2005.com

More information about the 2nd General Assembly of the WFDB

Charlotta Göller, International Secretary
WFDB c/o FSDB, SE-122 88 Eskede, Sweden
tel. +46-8-39 9155, fax: +46-8-659 5042
e-mail: lotta@wfdb.org
www.wfdb.org

REGISTER NOW!

The 6th Dbl European Conference August 2nd – 7th 2005 in Prešov, Slovakia

If you have not already registered please do so as soon as possible.

Visit – <http://www.dbiconference.sk>
or email conference@dbiconference.sk

THE AIM of this conference is to address the challenge of making deafblindness and deafblind people more visible – and to provide participants with better resources to develop their work. The Scientific Committee has designed a format that will help participants to address more deeply a specific topic and enable exchanges and collaboration with colleagues on this topic throughout the conference. Each participant will attend a mini-conference (a stream) along with the plenary sessions and free paper presentations. The streams are:

- Acquired Deafblindness
- Charge Syndrome
- Communication

- Congenital Deafblind Adults
- Early Intervention
- Educating Children
- Elderly
- Employment
- Interpreter development
- Families
- Leisure and play
- Service development
- Staff development
- Usher

For all information about this conference please visit <http://www.dbiconference.sk> or contact the Conference Secretariat:

A&D Global Business Relations – Attn: Anna Misinova

P.O. Box 208, Nam. legionarov 5, 080 01 Presov, Slovakia

Email: conference@dbiconference.sk; Tel/Fax: +421 51 7582 485

The UN Convention and Education

Lex Grandía brings us up to date on the important work at the UN and gives us a flavour of the difficulties encountered in getting the needs of deafblind children and young people recognised.

In the last issue of Dbi Review, I gave a short report on my work at the United Nations, on an international convention on the rights of persons with disabilities.

Here, I want to give a concrete example to show you what is going on. There have been major developments in the field of education. We all know that in the beginning of the 1990's we spoke about mainstream education and integration into the mainstream. These terms are now out of date.

It was felt, that as the term "mainstream" suggests, that there is another part left behind, that is not mainstream and not equal. It was also felt, that "integration" meant that the student, a child or an adult, has to adapt her or himself to the education system, and the classroom, to be able to participate.

Now the newer term "inclusive education" has become widespread. It means, that the education system, the classroom, has to be adapted to make it possible for every student to participate.

Agreeing a form of words!

One of the side-effects of the work on the convention, where many different disability organisations are involved, is, that the organisations have to try to agree on all articles, before going into the process of negotiations with the member states.

Organisations like Inclusion International and Disabled People International do not see any reason why some disabled people want to receive special education in special schools. They are very much against this as they are fighting hard to get inclusive education fully realised.

The World Blind Union, The World Federation of the Deaf and the World Federation of the DeafBlind (WFDB) are not against inclusion. As representative of the WFDB, I have defended the need of special education and schools, because of the use of sign language, tactile communication, Braille and mobility. It looks to me as an impossible and unequal situation for students with deafblindness, to be put in a classroom, without being able to communicate with classmates.

The discussions were very emotional, but finally, we managed to get a text, that we all agree on and that we will be supporting the coming negotiations with the member states.

Here it is:

Article 17 Education

PARTIES SHALL

1. recognize the right to quality education of all girls, boys, young people, women and men with disabilities.

2. With a view to achieving this right progressively and on the basis of equal opportunity for all, the education of people with disabilities shall aim to:

a) Build a society that is inclusive to all persons, including all girls, boys, young people, women and men with disabilities;

b) Recognize the full development of the human potential and sense of dignity and self worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;

c) Enable all persons with disabilities to participate fully and effectively in a free and inclusive society;

d) Support the development of the individual's personality, talents and abilities to his or her fullest potential;

e) Recognize and supporting individual learning needs;

3. STATES PARTIES SHALL

ensure that:

a) all (girls, boys, young people, women and men) with disabilities have access to inclusive and accessible education in their own community, including access to early childhood intervention and pre-school education;

b) the full and effective participation of persons with disabilities, through the provision of required support, including the specialized training of teachers and other educational means and staff, pre- and in-service training of regular, specialized and support teachers, an accessible curriculum, accessible teaching medium and materials, appropriate assistive devices, alternative and augmentative communication means and modes, sign language, alternative learning strategies, universally accessible built environment or other reasonable accommodations;

c) no child with disabilities is excluded from free and compulsory primary education on account of his or her disability;

d) all persons with disabilities shall have access to secondary education, vocational training, higher education, adult education and lifelong learning on an equal basis with all others, and to that end appropriate assistance and reasonable accommodation needs to be provided;

e) no person with disabilities shall be required to undergo any medical treatment or intervention to correct, improve or alleviate any impairment, or any actual or perceived disability, as a condition of inclusive and full quality education;

f) Students with disabilities are explicitly included in all national education and implementation plans, and that the same standards, objectives and curriculum are provided for persons with disabilities as for all other students in the general education system;

4. STATES PARTIES SHALL

ensure quality education for deaf, deafblind, blind, and partially sighted children and young persons:

a) Deaf and deafblind children and young persons have the right to receive education in their own language, in their own groups and to become bilingual in sign language and their national spoken and written language, learn additional foreign languages, both signed and spoken/written, have legislative, administrative, political and other measures taken by States' Parties to provide

quality education using sign language, thereby ensuring the employment of deaf teachers and hearing teachers who are fluent in sign language;

b) Blind, partially sighted and deafblind children and young persons, have the right to receive education in special schools or special classes for blind, partially sighted or deafblind children, to gain literacy skills, and to study a wide curriculum, including mathematics, geography and chemistry, with learning materials in Braille and/or through alternative formats including assistive devices, be provided with daily life skills and mobility training in parallel with the classroom education, in order to gain full independence and freedom, to receive an education provided by teachers with competence to teach communication skills and who have received training relevant to the specific needs of blind, partially sighted and deafblind children and young persons.

It's not the end

What states probably do not want, is the mentioning of Deaf, Blind and Deafblind people and they probably want to shorten it, but we will see!

For those who are interested in the developments, here is a website that is updated regularly:

www.un.org/esa/socdev/ENABLE/RIGHTS/ADHC4ngos.HTM

Lex Grandía

Management Committee News

The Dbl Management Committee meeting was held on 31st October and 1st November 2004. Many issues were discussed, including details of the forthcoming European Conference in Slovakia in 2005, results of the Network Survey and future Dbl Publications.

If you wish to request a full copy of the Management Committee minutes, please contact the Secretariat at secretariat@deafblindinternational.org

The major Dbl events coming up are:

The sixth Dbl European Conference will be held from 2nd – 7th August 2005 in Prešov, Slovakia. It is now possible to register online for the conference. Full details are available on the conference website: <http://www.dbiconference.sk>. We look forward to receiving those registrations!

The Dbl Asia conference that was due to take place in Nepal in November 2004, has been postponed as a result of the unsettled situation in the country. The Dbl

Management Committee is exploring options in the region to host an Asia conference in early 2006. We will keep you informed of all developments.

The next Dbl World Conference will be held in Australia in 2007.

Membership Update

The Secretariat has been working closely on monitoring the membership payments and we have received a high number of renewals for this year. Some members have taken advantage of the reduced membership fee for four years.

Members are advised to renew your membership, if you have not done so already. Please quote your specially assigned membership number in all communications.

There are 620 members, including 47 corporate members, from over 79 different countries.

We are happy to announce our new Small Corporate Members: 'Netherlands Knowledge Center for Deafblindness', 'Visio Het Loo Erf LSSB', 'Kalorama' and 'Bartimeus' from Netherlands, 'Shikshit Yuva Seva Samiti' India, 'National Centre for Deafblind Issues' Sweden, 'Anne Sullivan Centre' Ireland 'SZB Tuabblinden' Switzerland, and 'Danish Parents Association' Denmark.

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

If you have any queries regarding the status of your membership, please do not hesitate to contact secretariat at secretariat@deafblindinternational.org

The Dbl Secretariat

Since moving the Dbl Secretariat to India, much work has gone into further streamlining the systems so as to ensure an even better service.

Membership reminders for the next year will be sent soon to all Corporate and Individual members. Encourage your friends and colleagues to sign up as individual members of Dbl.

The circulation for the last issue of Dbl Review was coordinated by the Secretariat in India. If you did not receive your copy, please contact us.

If you have any queries regarding your current membership or would like to complete the membership form via email, please contact Sumitra at:

secretariat@deafblindinternational.org or post your query:

Dbl Secretariat,

Post Box No: 9601, Janakpuri,

New Delhi – 110058, INDIA.

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

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

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

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

There are now two tiers of Corporate Membership:

Large Corporates:

Annual Fees between £3,000 and £ 5,000

Small Corporates:

Annual Fees between £ 300 and £ 1,500

Corporate Members can be nominated to sit on the Council.

DbI Membership

Deafblind International Individual Membership

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

Member details Membership No.

Title Surname First name

Organisation

Job Title

Address (Line 1)

Address (Line 2)

Town/City State/County

Zip/Post Code Country

Telephone no. Fax no.

(Please include country and area codes)

E-mail address:

Are you:

a deafblind person – a family member a professional

Does your organisation work primarily for/with:

blind people deaf people deafblind people

disabled people other (please specify)

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

Dbl Review (please check one box in each category)

A. I would prefer to receive Dbl Review in:

English Spanish

B. I would prefer to receive Dbl Review on: paper disk*

(The disk version of Dbl Review is supplied in text only format, on floppy disk)

Membership Fee please tick where appropriate

I wish to pay an annual membership fee of £30

I wish to pay for 4 years' membership at the discounted rate of £100

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

Corporate Membership

There are two tiers of Corporate Membership:

Large corporates

Annual fees between £ 3,000 and £ 5,000

Small corporates

Annual fees between £ 300 and £ 1,500

We would like to join Dbl as a Large/Small

Corporate Member (please delete as appropriate)

We submit an annual fee of £

Corporate members are entitled to receive

up to 25 copies of Dbl Review. We would like

copies in English

Spanish

(delete as appropriate)

Member Details:

Organisation

Representative

Address (Line 1)

Address (Line 2)

Town/City State/County

Zip/Post Code Country

Tel:

(please include country & area codes)

Fax:

(please include country & area codes)

Email:

How to pay?

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

Payment method Bank Transfer Credit Card Cheque

A) Payment by Bank Transfer

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

Name of Bank: RABOBANK

Address of Bank: Sint-Michielsgestel, The Netherlands

Account Name: Instituut voor Doven: INZAKE DBI

Account Number: 11.29.09.825

Swift Address: RABONL2U

IBAN: NL31 RABO 0112 9098 25

Date of Bank Transfer:

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

B) Payment by Credit Card

Card type: VISA American Express Mastercard

Card no:

Expiry date Name on card:

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

C) Payment by cheque

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

Please fax this whole page to 91-11-25618430 or return to:

The Secretariat, Deafblind International, Post Box No 9601, Janakpuri, New Delhi – 110058, INDIA.

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The World Association Promoting Services for Deafblind People

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