

DbI Review issue 39

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

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

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

Photographs and drawings are welcome; they will be copied and returned.

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

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

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

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Cover: Lex and Shinichiro using finger braille at the UN

A message from the president

Dear friends and colleagues

Italy had the pleasure of hosting the Dbl Management Committee a month or so ago and we are working hard on a number of areas including the strategic direction of the organisation, nominations to office and awards to those who have given outstanding service.

The development of the strategic plan has been a lengthy and detailed piece of work, involving a small team from around the world. It will be presented to everyone in Australia later this year at the World Conference in Perth. Areas such as economic growth, roles and membership, collaboration, network development and much more will be discussed in depth. I would like to thank Tony and the team for all their hard work in producing this plan and Bernadette who has been closely involved throughout.

Another important element this year is the election and nomination procedure for a future new president, officers and council members. I am sure that much thought will be given to these important posts and I know the Nominations committee, led by Gillian Morbey, have been working extremely hard to consult with you. You will be reflecting upon their proposals – not an easy task. My personal thinking on this is that there are no winners or losers in this election. Just to be nominated or taken into consideration for a leadership role in our fantastic organisation is in itself a great honour.

One of the most pleasurable role of the President, is the job to present the Dbl awards during the next World Conference. You are asked to nominate people you feel merit these awards. Please use this possibility to acknowledge people from our field in this delightful and important way. Bernadette is managing this process and you will find all the information on pages 54-55.

We continue to proceed with our intention to collaborate with other agencies and progress is under way for the preparation of a Memorandum of Understanding with the WFDB. We hope to have a proposition for your approval later this year. You will be pleased to hear that we are enacting our MOU with ICEVI and we are looking forward to working more closely in the future.

On a slightly different note many countries are working on the recognition of deafblindness. This is truly an important task. I have found that we often use other countries experience to motivate our politicians at a national level. One of the first questions from governments is in which countries is deafblindness mentioned in law and in which way. May I propose that any country having such a law or recommendation send the wording to our Secretariat for the record.

As you know the next world conference is planned for Australia and I know that many people are trying very hard to get there. Our regular contact assures us that this Conference will stay in our minds and hearts for many years. Lastly on a sad note We have lost two wonderful colleagues – Jacquie Treffry McInnes and Norman Brown. Our brief tributes cannot do them justice and fill the gap they leave behind in our hearts and minds.

William

Editorial

The magazine leads off this time with a timely article about the UN Convention on the rights of persons with disabilities. It has been crafted to meet our particular needs and interests, by Lex Grandia. He has tried to help us make sense of not only the process (which has been labyrinthine), but the material too. He has picked out all the relevant pieces to whet our appetites enough to read the Convention in full. At the end he issues a challenge to everyone to take action by using it in our work. He also suggests that in working together we are much stronger. I agree with that. I have followed Lex and Ann throughout the time they have been working on this long negotiation, often meeting with exceptional problems and negative responses to their suggestions and proposals. New York sounds very romantic (and I'm sure it is!) but I know just how hard it has been for all the representatives and their interpreters. Thank you Lex, from all of us. I now look forward to DbI begin to plan in order to make this Convention have an impact for deafblind people wherever they live.

This time we have some great reporting of members ventures, new and old, curriculum ideas and research.

In all this celebration we also have the sad news that two very special individuals, much loved and respected, have left us. Their ideas and insights, I can safely say, reached right around the world.

Do keep me posted with your news. We can use the magazine and the website to share your ideas and information. The networks are a great place to begin your dialogue with others and thanks to the Secretariat, who do all the technical addition to the website, new facilities will soon be available to assist "e" conversation.

I look forward to hearing from you very soon

Eileen

The UN Convention on the Rights of Persons with Disabilities

The power to change the lives of persons with deafblindness around the world

At last we have the final version of the Convention and Lex Grandia, President WFDB, and a deafblind person himself, reports the results of years of hard work, which provides a huge lever for change

Introduction

The text of the Convention on the rights of persons with disabilities is ready! 191 states of the United Nations agreed on the text of this legal document. Deafblindness and the special needs of persons with deafblindness are mentioned in this Convention, which will influence the lives of people with deafblindness, their families and professionals world wide.

I will try to explain the background, outline examples of specific interest to the deafblind world, share my positions on them and propose ways to include deafblindness in the implementation process. We must all monitor the implementation of this Convention. Countries, which ratify this law, will have to change their national laws accordingly and we must all work together to ensure the inclusion of the needs of people with deafblindness.

Negotiations in the UN, the history of the Convention

It was only in 2001 that the General Assembly of the United Nations appointed an Ad Hoc Committee to start the work on a Convention on the Rights of Persons with Disabilities.

As international disability organisations, we wanted to participate in this work. Negotiating an international, comprehensive instrument about us, that is, disabled people, cannot be done without us, we thought. The UN rules and traditions did not view the disability organisations as partners in the process because usually a convention is negotiated among the member states of the UN. In the beginning of the process disability organisations were admitted to a few of the meetings of the Ad Hoc Committee as observers only.

After two meetings of the Committee, a Drafting Group was formed to produce a first draft text. In this drafting group the disability organisations managed to include 12 representatives from international and regional disability organisations to sit alongside the 27 state representatives. I was happy to represent the World Federation of the DeafBlind in the drafting group and later during the whole process of negotiations.

A lengthy process

This period of three years has been very intensive for me, and very productive for the field of deafblindness. Beside the intensive two or three weeks of meetings in the Ad Hoc Committee, intense and continuous e-mail consultations took place among disability organisations.

First of all the World Federation of the DeafBlind had to find allies among other disability organisations, and raise awareness about the needs of persons with deafblindness. I served on numerous occasions as a spokesperson for the international disability organisations involved in the work, known as the International Disability Caucus (IDC) and I was often appointed to chair meetings of the IDC. These occasions offered a unique opportunity to raise awareness of deafblindness everywhere.

During the process of negotiations in the UN, the 8 meetings of the Ad Hoc Committee and the extensive consultations between the meetings, disability organisations developed a more vital role in the Ad Hoc Committee and were increasingly consulted as experts by state representatives.

The final document is very close to the proposal of disability organisations.

The structure of a Convention

An international convention starts with a preamble, which is not legally binding but more a description of why the General Assembly of the United Nations has decided to create this international instrument and the intentions behind it. Here are some key points of the preamble:

“Recognizing that the United Nations, in the Universal Declaration of Human Rights and in the International Covenants on Human Rights, has proclaimed and agreed that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind,”

“Recognizing further the diversity of persons with disabilities,”

“Recognizing the need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support,”

The preamble reflects the major change in attitude to persons with disabilities, from disability as a charity or social issue to disability as a human rights issue:

“Concerned that, despite these various instruments and undertakings, persons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world....”

Of particular importance for Dbl and WFDB is the following:

“Recognizing the importance of international cooperation for improving the living conditions of persons with disabilities in every country, particularly in developing countries...”

The change of attitude is clearly expressed thus:

“Recognizing the valued existing and potential contributions made by persons with disabilities to the overall well-being and diversity of their communities, and that the promotion of the full enjoyment by persons with disabilities of their human rights and fundamental freedoms and of full participation by persons with disabilities will result in their enhanced sense of belonging and in significant advances in the human, social and economic development of society and the eradication of poverty,....”

Legal capacity

This Convention is a legal document, an agreement between states, to implement the articles of the Convention and to change the national laws according to this Convention. The Convention has 50 articles covering all aspects of life: the right to life, health care, education, accessibility, work and employment, living conditions, family life, politics and leisure.

One of the parts of the convention which is very important for people with disabilities, and in particular for persons with deafblindness, is Article 12, about legal capacity, because the legal status of persons with deafblindness is clearly

related to all articles.

Its states that,

“Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.”

”Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.”

It means that all persons with deafblindness have the right to act as any other person, i.e. signing documents and contracts or owning property, even if the person (in the eyes of other people) is not able to represent her or himself. Instead of guardianship, the international disability organisations have promoted a model of supported decision-making. Guardianship means that somebody else is making decisions on behalf of a person with a disability, without consulting the person. The international disability organisations wanted to make sure, that all decisions made on behalf of a person with disability is supporting the person and the final article reads:

“Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”

“Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.”

This article is very important. Some persons with deafblindness have difficulties in expressing their needs and wishes, but still the new convention underlines the obligation of states to provide the necessary support in the decision making process.

Guiding principles

The aim of the Convention was not to grant people with disabilities new human rights that others do not have, but to draw up a legal way to move from being an object of charity to a subject, a person, a full member of society. The phrase self-determination was proposed during the negotiations, but later discarded because it refers to the self-determination of states in international law. The Convention formulates some basic attitudes and principles, that are needed to change society.

These principles in Article 3 make the Convention even broader than an agreement between states:

“Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons; Non-discrimination; Full and effective participation and inclusion in society; Respect for difference

and acceptance of persons with disabilities as part of human diversity and humanity; Equality of opportunity; Accessibility; Equality between men and women; Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities..”

Article 17 says:

“Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.”

In this line the Convention has articles against degrading and inhuman treatment and all forms of exploitation and abuse.

What the Convention says about Communication

In Article 2, definitions, the description of communication specifies different modes and types of communication, some of them vital to people with deafblindness. Thanks to the initiative of the representative of Uganda, tactile communication was included in this description:

“Communication” includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology;”

Everywhere in the Convention, where the word communication is used, it refers to the description above.

The Convention recognizes Braille as a script. There was a widespread belief among state representatives that Braille is not necessary anymore, it is replaced by speech technology. To omit Braille would have been a disaster for deafblind persons using Braille.

Freedom of Expression Article 21

The use of Braille is about reading, and about the right to express oneself in writing.

“Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of “communication” of their choice, as defined in article 2 of the present Convention,”

(referring to the definition above)

Sign Language Article 2

After long and tough negotiations, sign languages were internationally recognised in the Convention. There are several references to sign languages.

A part of freedom of expression is the right to express oneself in the language and mode of choice including sign languages and tactile communication as stated in article 2.

“Language includes spoken and signed languages and other forms of non-spoken languages”

One of the measures that States have to undertake to ensure freedom of

expression includes:

“Recognizing and promoting the use of sign languages.”

Accessibility Article 9.

Accessibility is covered in article 9, as well as a cross-cutting principle in all the articles of the Convention. Access to all kind of services including justice, transportation and buildings. For people with deafblindness access to information and information and communication technology is very important. Of particular interest to DbI and WFDB is the obligation to:

“Provide training for stakeholders on accessibility issues facing persons with disabilities;”

as well as:

“Provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;”

Health and (re)habilitation

In many parts of the world people, children with deafblindness, barely have access to the basic health care. With this Convention there is hope:

“ Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability”.

“Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation”

One of the measures mentioned which is crucial for all deafblind people is:

“Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons”

In the beginning of the negotiations rehabilitation was related to health. It took a long time to make clear, that not all people with disabilities are ill. Therefore the article about rehabilitation is separated from the article about health. It is important for the deafblind world to have this specific mention of rehabilitation in the Convention, since we are just in the beginning of establishing rehabilitation programmes for persons with deafblindness in most countries:

“Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.”

and rehabilitation measures shall:

“begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;”

Living conditions

The enormous poverty of persons with disabilities is a big challenge to States. Here the measure “progressive realisation” was introduced. This means that some of the rights – the so called economic and social rights – will be implemented gradually, according to the financial situation of each country. It will take time before people with deafblindness in all countries of the world will have:

“access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care;”

Many persons with disabilities are living in institutions against their will. The disability organisations fought for very strong articles about the right to live where and with whom a person wants and:

“In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.”

In some countries there is a strong movement for persons with disabilities to live independently, whereas in many other countries it is more important to be a respected member of the family. The Convention reflects both views.

Education Article 24.

All states agree on the fact that all forms of education and life long learning should be inclusive. Inclusive education means that all can participate and the education system has to adapt to the needs of every individual. Article 24 about education is extensive and very precise. The World Blind Union, the World Federation of the Deaf and the World Federation of the DeafBlind were challenged here. We wanted the right to have education in our own settings. We need to be able to communicate, to learn our own communication systems, Braille, mobility and every day life skills in our own ways. This text is the compromise which was agreed on:

“Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:

(a) Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;

(b) Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;

(c) Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development. “

Awareness Raising Article 8

Recognition of deafblindness and awareness raising are still much needed. A

part of awareness raising is identifying challenges and the barriers in society, experienced by persons with deafblindness. The change of attitude is reflected in the way persons with disabilities are described in the article 8 of the Convention putting a duty

“to promote awareness of the capabilities and contributions of persons with disabilities.”

And:

“to promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market;”

Deafblind people as creative artists, performers and communicators
Article 30

“Parties shall take appropriate measures to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society. Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.”

Personal assistants and staff training

In many articles in the Convention, the right of persons with disabilities to be provided with assistance is spelled out. WFDB fought hard to include specific reference to personal assistance, which is so important for persons with deafblindness, in the Convention. One of the measures to improve quality of living, article 19, states that:

“Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;”

Promotion of training of professionals Article 4

“To promote the training of professionals and staff working with persons with disabilities in the rights recognized in this Convention so as to better provide the assistance and services guaranteed by those rights.” and:

“States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.”

Last but not least, I should mention the general obligation in this Convention, to involve persons with disabilities in all programmes and actions and legislations concerning them.

What will happen now?

The Convention has been adopted by the General Assembly of United Nations. On the 30th of March 2007, the Convention was open for signing.

Until now 85 countries have signed the Convention, and the number of countries is growing, making the Convention a big success.

Only one country, Jamaica, has ratified. By ratifying a country expresses, that as soon as the Convention gets into power, the country will be legally bound by it. The process from signing to ratifying the Convention is under way. Now national and federal laws are going to be changed according to the Convention. When 20 countries have ratified the Convention it will come into power for the countries that have ratified it.

In conclusion

I have here selected only a few articles. The Convention has also rules about how the implementation of the Convention is monitored and systems of filing complaints, when the human rights of people with disabilities are violated.

It is time for us to make sure that persons with deafblindness, of all ages, are included in all the new provisions and national laws. It is now the time for all of us, members of Dbl and WFDB to start acting on a national level on behalf of us all.

What can we do?

The first thing is, of course, to read the convention text. It is until now available in the 6 official UN languages: Arabic, Chinese, English, French, Russian and Spanish. Then we can:

- start to monitor carefully what governments or authorities are planning to change

- follow the media, use the contacts we have and focus on laws and provisions, that are important for us

- establish an e-mail list, where those interested can exchange information and ideas and examples of good practice

- set up a formal campaign

- include this information and call to action in all our conferences

Our deafblind group is small compared to other groups. It may be good to find allies among other groups: the blind, the deaf, intellectual disability groups.

As the president of the WFDB I am still deeply involved in the process of the ratification and implementation of the Convention. I still get 100 emails a day about the Convention. I invite all of you to participate.

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**The full text of the Convention in 6 languages to be found on
www.un.org/esa/socdev/enable/conventioninfo.htm**

UN Signatories (as of 11/04/07)

These countries also signed the Optional Protocol (for the international monitoring body)

Algeria*

Antigua by Barbuda*

Argentina*
Armenia*
Australia
Austria*
Belgium*
Brazil*
Canada
Cape Verde
Chile*
China
Colombia
Congo (Republic of Congo)*
Costa Rica*
Croatia*
Cyprus*
Czech Republic*
Denmark
Dominica
Dominican Republic*
Ecuador*
Egypt
El Salvador*
Ethiopia
Finland*
France
Gabon
Germany*
Ghana*
Greece
Guatemala*
Guyana
Honduras
Hungary*
Iceland*
India
Indonesia
Ireland
Israel
Italy*
Jamaica*
Jordan*
Kenya
Liberia*
Lithuania*
Luxembourg*
Macedonia (FYORM)
Malta*
Mexico*
Moldova
Morocco

Mozambique
Netherlands
New Zealand
Nicaragua
Niger
Nigeria*
Norway
Panama*
Paraguay*
Peru*
Poland
Portugal*
Republic of Korea
San Marino*
Seychelles*
Sierra Leone*
Slovenia*
South Africa*
Spain*
Sri Lanka
Sudan
Suriname
Sweden*
Syrian Arab Republic
Thailand
Tunisia*
Turkey
Uganda*
Uruguay
United Kingdom
United Republic of Tanzania
Yemen*
European Community

Some of the challenges can be addressed!

Dr Ruma Chatterjee, Director, Project Deafblind, Society for the Visually Handicapped, Kolkata, India reports the exciting work being established as a direct response to the needs of children and their families!

Yes, they are sometimes in front of me, sometimes behind—but always they are there to say ‘do something for us’! Most of them cannot see and hear or

speak. Like everywhere in the world, they are the most marginalized among the children with disabilities. In the heart of the city of Kolkata, we have come across 25 such children who require specialized training in the form of 'education for life'. 75% of them still do not have clinical diagnosis of their disabilities from medical experts/government hospitals.

Our journey began with Souvik Ghosh, a deafblind boy of 10 years, in 2004. His father was referred to our Tuesday Braille class by a teacher from a recognized school for blind children in Kolkata. The teacher was utterly confused about the boy's training. The parents were in the dark about the possibility of any kind of intervention into the child's world of 'invisible silence'. So, I took up the challenge based only on information about Sense International (India) and its work with deafblind children in India. But more than that I didn't know and I certainly had no information about which agencies work as their partners! But this initial contact involving my academic and technical involvement with SI (I) for more than two years later provided the motivation for my organisation to develop "Project Deafblind". It started with these children. And they are the real driving force in adopting this project.

The Society for the Visually Handicapped has completed one year in partnership with SI (I). In the December of 2005, we were working with three deafblind children, of whom one is in a private orphanage. That number has increased to 25 children and 12 are in an orphanage run by Missionaries of Charity. All of these children are between 5 and, 11 years of age. Last year we worked with each and every child separately in separate corners of a big hall. Structured work with 3 teachers for three days a week gradually transformed these children from 'active resistance' to 'tolerance/passive cooperation', and even to 'enjoyment'. Now, they recognize their teachers and are very happy with them. Some of them even demand 'more' work from the teacher! From January of this year, we have incorporated 'circle time' with these children. There are some problems regarding infrastructure of the room, but this will be sorted out in the future. Now the Sisters are very cooperative having witnessed the visible changes in some of the boys who otherwise show 'challenging behaviour'. For example, Sunil, a boy of 11 years used to pull the hair of the teacher or bite the sleeves of her kurta at the beginning. His attention span was so low! Now he is comfortable with his teacher, Piali, and demands more work! Visible changes are seen in Nilaya who used to cry and became angry when any one touched her. Now she allows her teacher, Ila, to train her in self-care practice. What is interesting and developmentally significant is that the care-giver's practice of feeding her with rice-gruel is totally rejected by her; she only takes rice which can be chewed!

Coming back to Souvik's story, he has shown remarkable signs of progress with continuous efforts put by Tapasi, his first teacher and now by Mitalee. In my opinion, Souvik is very intelligent and sensitive and keeps on giving gestures/signs for his desires/dislikes. Probably, most of these are not recognized by the family members in spite of their best intentions. After prolonged waiting, he starts showing his irritation (eye poking/head banging – self stimulation or whenever he can catch hold of any one, he starts striking). He not only recognizes Mitalee when she visits his residence in the morning, but also when occasionally she visits him in late evening. With a high powered Hearing Aid he can listen to the song and responds to the tapping of feet by Mitalee. During summer days, he is taken to a local pond by his father. He

loves to be bathed in pond water. But what is striking is his understanding of the change of activity when his teacher takes him to the pond and allows him to touch his feet only in pond water!

In an attempt to introduce our children to a winter outing, our teachers organized a picnic this January. Children, their parents or care-givers, volunteers and SVH members all joined in. The children enjoyed it so much! It was also a learning experience for us because the authorities of the Science City Park and caterers came out with their supportive hands to make it a success and it became a meaningful event for their activities too!

Reaching the Unreached: Project Deafblind is a home-based programme initiated by Society for the Visually Handicapped in Kolkata and its suburban areas. At present 3 teachers are working with the children. One teacher is undergoing Diploma Course in Mumbai. Two more trainee teachers are incorporated so that they can also join the Project in future.

Avoiding common errors in the use of calendar schedules as a teaching/learning strategy with persons who are deafblind

Nina Akuorkor Afutu, from Ghana, reports the findings from her study of the use of calendars systems and offers some sound advice

Many researchers have described calendar schedules as a process set out to prepare a deaf blind child/learner for a particular activity. (Jones, C.J. (2002): Karnad, D. (1999-2000): Siegel-Causey, E. & Guess, D. (1989). Calendars have a variety of sections with symbols such as objects, pictures, printed words or Braille based on the needs of the individual child.

The researcher's observations were made while on a training programme in the USA. She observed the use of calendar schedules from different programmes in the USA and made a comparison with what existed in her own country. This revealed that people with little, or no experience, make common errors in the quest of using calendar schedules as a teaching/learning strategy with persons who are deaf blind.

Some of the common errors observed were:

- inappropriate design of calendar without a different container to signify the end of an activity.
- use of symbols in the calendar to perform actual activities.
- leaving sections of calendar segment or compartment blank.
- calendar schedules not being designed in a sequence.
- use of different symbols for one activity.
- use of one symbol for different activities.
- failure to involve the learner in setting up the daily calendar schedule.
- skipping the sequence.

Learning from the study

The writer would like to share with teachers, caregivers, families and parents who have little or no experience in using calendar schedules in the daily routine activities of deaf blind persons to avoid such errors.

- It is inappropriate to design a calendar without a container signifying the end of the activity. The container signifying the end of the activity should have a different texture or size from all the other containers. On the other hand, those using calendar books or folders must have a finished pocket attached to the back of the book or folder where activity symbols should be put when the activity is ended.

- Symbols in the calendar should not be used to perform the actual activities. The child/learner can carry the symbol to the activity area. For example, if a spoon is used as a symbol for lunch in the calendar that same spoon as a symbol should not be used by the learner for the activity. Another spoon should be given to the learner to use.

- All calendar segments or compartments must be filled with the appropriate symbols for the day's activities. Do not leave a section of the calendar blank. For instance, if you have a four-item calendar, do not fill three of the segments, leaving one. If sections of the calendar are left blank it does not make it complete and the learner may not understand why there should be a blank section and would take it that calendar schedules are designed that way. Teachers, care givers, families, parents and all who work with persons who are deafblind must remember to design the calendar schedule in a sequence with the finished container always on the extreme right and must be different from the other containers.

- Do not use different symbols for one activity. For example, if a spoon is used for lunch time maintain it. Use of different symbols for the same activity creates confusion to the learner.

- One symbol should not be used for different activities. For example, do not use a toy earphone for music as well as audiology, or a napkin as a symbol for cleaning the hands and then the same symbol as towel for bathing. The learner may become confused and the meaning associated with a symbol to an activity would not be comprehended.

- Do not display all activity symbols on the shelf to create mess but organize only those that the learner will need at a time.

- Concrete symbols should not be changed instantly without making the learner aware of the change. For example, if a learner uses objects and is to move on to use print or Braille as calendar symbol, the objects and the print/Braille must be paired until such a time the learner understands the print/Braille it is then that object symbols can be faded out.

- Do not set the calendar without involving the learner. Any time the learner accomplishes an activity review the schedule before he/she moves on to the next activity.

- Do not allow the learner to skip the sequence, guide him/her to follow the sequence the way it has been in order to be consistent.

In Conclusion

In conclusion the following points must be adhered to when setting up a calendar schedule.

- All calendars should be designed with a finished container/pocket.
- Symbols in the calendar should not be used in performing activities.
- All segments of calendars must be filled.
- Calendar schedules should follow a sequence.
- One symbol should not be used for different activities.
- Similarly, different symbols should not be used for one activity,
- Skipping of sequence should be avoided.
- Involve the learner in the daily setting of the calendar.

By doing all these, learning becomes interesting and meaningful to the learner.

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The Vestibular Sense

David Brown continues with his series of articles highlighting some of the less well-known senses

Function

Our other sensory systems provide information about ourselves or about the environment around us, but the Vestibular system is unique in providing a continuous flow of information about the 'fit' between the two, the person and the environment; it tells a person how they are interacting in the environment and it enables the individual to remain oriented in space and in time. This is the sense that tells us about the position of our heads in relation to the pull of gravity, it tells us which way is 'up', and it detects motion. As a consequence of this it monitors and directs muscular activity and body position to maintain secure and functional postures whatever we are doing, working very closely with the touch and proprioceptive senses. It also has very close links with the visual sense, in particular stabilizing the fixation point of the eyes when the head moves which enables us to maintain a stable visual image of the world as we move. Since the Vestibular system only provides information about the position and movement of the head it relies on well-integrated links with the senses of proprioception and vision to facilitate postural adjustments in the rest of the body. If, for any reason, the Vestibular system is not working then these other two senses (vision and proprioception) can, with great conscious effort, be made to compensate to some extent and provide a degree of postural control and security.

Two writers give interesting broader perspectives on this sensory system that really emphasize the great extent of its contribution to all of our functioning: “In the final analysis, one may have a well-developed sensory map of the external world and a well-developed motor map of movement from one place to another, but if one does not know where they are with respect to that map, they are virtually incapable of using that spatial mapping information. And the Vestibular system appears to be the system that gives information about the individual’s location in the overall spatial map” (neurologist S.J. Cool in 1987).

Jean Ayres, an occupational therapist and the creator of Sensory Integration Theory and Therapy, is more concise and states simply that:

“The Vestibular system is the unifying system. All other types of sensation are processed in reference to this basic Vestibular information. The activity in the Vestibular system provides a framework for the other aspects of our experiences.”

Most importantly, Ayres declared that the Vestibular sense plays a key role in helping us to develop effective self-regulation of our arousal level, our ability to maintain a calm but alert state. So this is a sensory system that plays an extremely important role in enabling us to do almost everything that we do in our daily lives, and yet very few people know about it. In sensory terms, this is the big one.

Structure

The Vestibular apparatus shares space in the inner ear with the cochlea, which is part of the auditory system. The Vestibular apparatus is divided into two sets of receptors to monitor the two different kinds of head movement, angular acceleration (which happens when we shake or nod our heads, bend over, or roll over in bed) and linear acceleration (which is what happens when we are in an elevator moving up or down or in a car moving forwards). Let’s look at these two sets of receptors.

The semi circular canals

First the semicircular canals. There are three of these in each inner ear, arranged at right angles to each other so that they meet up in just the same configuration that two walls and the floor meet in the corner of a room. These angles correspond to the three planes in which we move (horizontal, vertical, and on the diagonal), so each of the three semicircular canals is designed to detect motion in a single plane. Their job is to detect angular acceleration of the head and by acting together as two matching sets, one left and one right, they tell our brains exactly what position our head is in at all times, and what direction it is moving. The matching sets of Vestibular apparatus on each side of the head are designed to work together, of course. If infection or damage causes the semicircular canals on one side of the head to send the brain information that disagrees with information sent by the semicircular canals on the other side of the head, then the brain gets confused about what the head is doing and the resulting conflict will lead to feelings of vertigo and nausea.

The vestibulo-ocular reflex (VOR)

As they monitor all movements of the head, the semicircular canals also organize compensatory movements of the muscles that control eye movements, so that the fixation point of the eyes remains on a stable base rather than moving about the same as the head; specific head movements trigger specific semicircular canals to activate specific pairs of eye muscles in specific ways that enable this. This is a remarkably complicated but quick acting reflex sequence. The amazing thing is that although it stabilizes our visual fixation for us, we can then superimpose voluntary eye movements upon this stable base whenever we wish to. This compensatory reflex, complex and smooth and rapid, yet something that we don't need to think about at all, is called the vestibulo-ocular reflex. You can identify the reflex at work with a simple experiment. If you hold a book very still and try to read part of it as you move your head side to side and up and down and round in circles, it might not be particularly comfortable, but it is perfectly possible to keep your eyes reading and following the lines of print, thanks to your semicircular canals which are being activated by your head movements. But if you keep your head absolutely still and somebody else keeps moving the book around in front of you it is impossible to read along the lines of print since your semicircular canals are not being activated by any head movements, and your voluntary eye movements are totally incapable of keeping pace with the movements of the lines of print in the book. This gives you a small idea of what it must be like to try to use your vision when the semicircular canals are damaged in some way.

The utricles and the saccules

The other set of receptors in the Vestibular system are two sack-like structures called the utricles and the saccules. The utricles lie horizontal when the head is upright and they detect linear motion in the horizontal plane, while the saccules lie vertical in the upright head and they detect movement up and down and forward and back. These two pairs of organs keep us vertically oriented with respect to gravity, and any movement away from upright triggers the head-righting reflex, which leads to correcting postural adjustments. When we think we are standing quite still and vertical we are, in fact, rocking very slightly back and forth or side to side in order to trigger this reflex to help us to maintain correct vertical posture.

The Equilibrium Triad

Postural and gravitational security, and a good sense of equilibrium, both depend upon the effective development and functioning of three different but interdependent sensory systems (an "Equilibrium Triad"), namely the vision sense, the Vestibular sense, and the combined tactile/proprioceptive senses. For many children with deafblindness, especially children with CHARGE syndrome, all three of these sensory systems are likely to be missing, impaired, or malfunctioning, which largely explains the slow development of large motor skills and mobility, but also makes it remarkable that so many of these children do eventually stand up and walk. The good news is that any

input and experience that helps to improve the functioning of any of the sensory systems in this Equilibrium Triad can, therefore, be regarded as making a contribution to the development of good postural control that might result in independent standing and walking – it is not only about the Vestibular sense.

Why does the Vestibular sense go wrong?

- A damaged, or missing, Vestibular system.
- Cerebral palsy and other sorts of brain damage which result in abnormal muscle tone, limited movement abilities, and problems with tactile and proprioceptive perception.
- Certain infections, medications (and alcohol!).
- Over-stimulation (for example, motion sickness), which can result in feelings of nausea and vomiting.
- Blindness, low-vision and visual perception difficulties.
- Lack of use resulting from movement difficulties, from feelings of insecurity and fear, or from a generally low level of motivational drive due to limited stimulation, limited sensory perception, or ill health. Like all sensory systems, if the Vestibular sense is not stimulated, challenged, and used it will not develop effectively.

The Vestibular sense and deafblindness

When we look at the list above it is possible to imagine that many children with deafblindness will have difficulties with their Vestibular perception, either because of malfunctioning or absence of the Vestibular apparatus (as is common with CHARGE Syndrome, for example), or because of other issues that are on the list. Because the Vestibular apparatus plays a crucial role in organizing sensory perception through all the other sensory channels this problem has a profound effect on all areas of functioning and behavior for the entire life of the child. However, its importance and impact is usually overlooked and under-played, especially once the child is standing and walking independently.

Jean Ayres realized a long time ago that knowledge of Vestibular function was crucially important when considering a child's visual difficulties. In 1981 she wrote that as early as the mid-60s:

“We could see that visual processing problems were central to learning disorders, but we needed to look beyond vision. If you just look at children from a behavioral standpoint and do behavioral type research and modeling, you'll never really discover that a main foundation to visual perception is the Vestibular system, with proprioception and other senses also contributing.” She went on to discover more about the central importance of this sensory system that we all need to study and understand if we are to work successfully with children with deafblindness. Here are some of the important connections:

Vision

So there are strong links between the Vestibular sense and vision, as already explained. Problems with Vestibular perception may affect the ability to

maintain a stable visual field, but it may also make it difficult to follow objects smoothly with the eyes as they move, and to differentiate whether it is the object or oneself that is moving. Some children may appear to 'go blind' if their postural security is too challenged, but they may surprise us by showing some well-developed visual (and other) skills once they are flat on their back or on their side on a stable surface. This apparent paradox shouldn't surprise us because Jean Ayres told us a long time ago that, after air to breathe, postural security is our next most urgent priority; without postural security none of us is going to focus our attention on reading a magazine, or on listening carefully to a radio broadcast, or on carrying out a complex fine motor task like sewing or writing. First we save ourselves from falling, or reorganize our position to get more secure and physically comfortable, and then we do our reading or listening or sewing. As they get older, children may use residual vision to help them to stay upright (think about the Equilibrium Triad), compensating for having a poor Vestibular sense by using the strong visual impressions made by horizontal and, especially, vertical lines in a room (for example corners, the edges of windows, doors, table tops, and wall-mounted pictures). They may have much less equilibrium outdoors where these strong visual markers are largely absent or beyond their range of vision. One result might be a reluctance to go outdoors, for example during recess at school, and another might be an inability to perform certain tasks when they are outdoors that they perform very well indoors. For children who are reading, the use of a typoscope (a letter-box shaped frame) can help by isolating one single line of text at a time. Similarly, the use of large print on a computer might be very helpful to a student, not because their visual acuity is poor but because they need help to isolate the line of text on which they should be visually fixating. In addition to vision, the Vestibular sense links with many other areas of functioning:

Hearing and understanding sequencing

There are links between the Vestibular sense and the ability to process sound, to perceive and remember auditory sequences, and so to develop spoken language. For children with Vestibular issues this has implications in addition to other hearing difficulties, and a truly collaborative approach that brings together a teacher of the deaf, a speech therapist, and an occupational therapist trained in Sensory Integration Therapy (or any combination of these) should be very helpful. Difficulties processing auditory input contribute to problems with language development, and also to problems with memory and with learning many basic academic skills. We all need to move to some extent in order to listen, but children with Vestibular problems may need to move even more to listen and to understand, so that, when they are standing, telling them to "Stand still and listen" could be counter-productive. Understanding and remembering visual and movement sequences are also likely to be more challenging if the Vestibular sense is significantly impaired.

Memory

An absent Vestibular sense is likely to have a negative impact on the development of memory, which, with the difficulties with the effective use of

vision (especially fine central vision), and with the processing of auditory input, will have a cumulative impact on speech and language development, and on receptive understanding of visual language (for example sign language, finger spelling, written language). Resultant difficulties with expressing themselves, or the constant experience of having their expressive communications misinterpreted, can lead some children to give up, or to resort to explosive behaviors that may be construed as unpredictable, irrational, or emotionally disturbed. Significant problems with the Vestibular sense can also inhibit the development of effective body language, since postural control, equilibrium, muscle tone and motor coordination will all be impacted.

Attention/ distraction and levels of arousal

If arousal levels are abnormally high or low, and the child has very limited ability to self-regulate because of problems with the Vestibular sense, they may never attain that 'calm but alert' state that is essential for effective learning.

Muscle tone/ postural control and security

Very persistent low muscle tone is often associated with severe Vestibular problems. Low tone is also associated with low vision, breathing difficulties, and generally reduced sensory inputs, hence reduced perceptual awareness. The problem is then compounded by the lack of motivation to move and the resulting lack of "exercise." Protective reactions, standing, cruising, and independent walking usually develop very late. When children do walk, there is often a characteristic gait, some aspects of which may remain evident for many years – the feet spaced widely apart, the knees bent to lower the center of gravity, the body rolling from side to side with each step, the feet sliding along the floor or planted down very firmly on the floor with each step (maybe several times, almost like patting the floor with the foot), and the arms held up like a tightrope walker. Some children walk with repeating swaying circular movements of the upper body and head, as if trying to keep aware of the danger areas at the limits of safe posture by alternating from one 'danger' position to another. On-going monitoring by a physical therapist is important because there is a high risk of the development of neuromuscular scoliosis (curvature of the spine) in childhood and the teenage years.

Bilateral coordination/ orientation and mobility

Bilateral coordination, the ability to use both left and right sides of the body independently and also together, may be significantly affected, with one side so dominant that the other side of the body is ignored. Hand dominance and eye dominance may be very late developing, or one hand and eye might be so dominant that the child is effectively functionally one-eyed and one-handed. Remember also that, when it is working effectively, this is the sense that tells a person how they are interacting in the environment, enabling them to remain oriented in space and in time. Add these challenges to blindness, and to poor body awareness due to limited tactile and proprioceptive feedback, and it seems amazing that many children with deafblindness do manage to learn and

remember routes at all.

Breathing/ feeding skills/digestion and nutrition

Because of resultant low tone, poor head control, preferred horizontal postures, and limited movement, these are all likely to be adversely impacted.

Sociability

As can be seen from this list, significant difficulties with the Vestibular sense cause disorientation and confusion in most aspects of daily living, particularly when there are other sensory impairments present also. Unless people involved with the child are prepared to understand these difficulties and adopt a supportive and non-judgmental attitude, then the child is likely to develop a strong distrust and dislike of others. This is especially regrettable when people repeatedly stop the child doing the very things that enable them to function – things like adopting specific postures or using self-regulation strategies that are interpreted negatively as ‘self-stimulating behaviors’.

What can we do to help?

- Respect compensatory behaviors as functional, and help the child to make their own choices. Prohibit anything dangerous, of course, but otherwise do not attempt to remove or replace any of these compensatory behaviors until their function has been established.
- Suggest evaluation by an occupational therapist (preferably trained in Sensory Integration Therapy) and a physiotherapist, and implement their suggestions. Regular input from therapists is very important for all children with Vestibular dysfunction, but these therapists will need to be informed about the existence of severe balance problems and about the implications of this.
- Pace activities to facilitate optimal functioning and to minimize fatigue and stress. Functioning with little or no Vestibular information is an extremely challenging and tiring business, so breaks and rest periods may need to be frequent and extensive.
- Remember that work that improves the functioning of other sensory channels can help to ameliorate the impact of Vestibular difficulties.
- Younger children, and those with physical disabilities, may need to be lifted and carried, which could be very threatening for them if they have poor Vestibular functioning combined with other sensory impairments. Handle them to minimize stress, for example, by using consistent anticipation cues, using an appropriate speed & direction of movement, and providing adequate physical support for both the head and the limbs during movement as well as for the child’s body.
- Always make appropriate physical support available (for example, seating, a table, things to lean against, or you yourself). As these children get older the problems with fatigue, postural control, and sitting or standing unsupported may be less evident but still present. Sometimes the student will benefit from using an adapted chair, with arms and a footrest, possibly also with the seat tilted forwards to encourage more active sitting against gravity. Alternately, some children may benefit from provision of mobile seating such as a suitably

sized therapy ball, which can facilitate repetitive rhythmic motion of the lower trunk and legs which helps the brain to know where the body is and that it is all secure and under control (rather like the way we all sway around slightly when we think we are standing quite still). There may still be a great need to support the head by propping it up or by resting it on one or both arms or even down on the desktop itself, in order to read or write. Also remember that extended periods standing still and entirely unsupported are usually particularly challenging.

- Allow periods of movement or repose, as appropriate, for reorganization of the whole body and all its sensory systems. Some older children and teenagers can seem to function quite well at their desk for extended periods of time, but they then need periodically to get up and move around, or to get into a horizontal position to relax and to re-charge their energy levels for the next exertions. They may also need periods in the horizontal position to reorganize their sensory systems using behaviors like leg kicking, hand flapping, shoulder shrugging, hyperventilating, or gazing at bright light.
- Observe for indications of under-arousal or over-arousal and know what to do about it (if the child cannot do this themselves).
- Think about the total demands made on the child by every activity in every situation (in other words, think multi-sensory). Many otherwise well planned activities fail because the child is being challenged or distracted by a sensory challenge that has not been noticed by the adults involved with them.
- Isolate lines of text (for example, large font on screen, typoscope) if necessary.

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Welcome to

The 6th EBU Deafblind Conference

“ Deafblindness: Equality and Diversity “

and

The 2nd EDBU General Assembly

25 – 30 April 2008

Four Points Panorama Hotel, Zagreb, Croatia

More information coming up!

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Rubella Network

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The siblings Network

Having a deafblind brother or sister has a big impact on the lives of siblings. It is important that parents and professionals, as well as the deafblind brothers and sisters realise this.

The Siblings Network is working hard to raise more awareness for the special situation in which these children grow up.

During workshops we can offer support, give time to share experiences and to learn from each other. Furthermore we would like to start talking about our role as a sibling and our role as a guardian when parents cannot take care anymore.

Hope to see you in Australia!

Sabine Kersten
Siblingsnetwork@gmx.net

ADBN

The Co-ordinating group of ADBN met in Bergen, Norway in April; the first meeting since the highly successful 5th International Seminar of ADBN, which took place in Groningen, Netherlands, in November 2006. The group reviewed the seminar programme and delegate feedback and was pleased to learn that responses from the 168 delegates were extremely positive. This fed into preliminary discussions about the content for the programme for the 6th International Seminar, which will take place in Bergen in November 2008. Representatives of the Norwegian planning group were on hand for the April meeting to share early ideas and suggestions.

Please note in your diaries that the 6th International Seminar of ADBN will take place from 29 October – 2 November 2008.

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Usher Study Group

DbI Usher Study Group first meeting in Australia
'Out of isolation and into the worldwide Usher family'

Monday Sept. 24th to Tuesday 25th Sept. 2007

at Burswood International Resort Hotel, Perth, Western Australia.

People with Usher syndrome have many experiences in common. Although their environments, social setting and geography differ widely, what people experience with regard to hearing, balance and changes in vision follow fairly predictable patterns. This Usher Study Group aims to dispel the sense of isolation by sharing common experiences and new knowledge.

Programme topics will include – families and clinical research, advances in molecular genetics, building networks and e-groups, staying in employment.

The scientific papers will be accessible to people from non-medical backgrounds.

The USG is of interest to anyone with a working knowledge of Usher syndrome in particular professionals from health, education and social work backgrounds, to people who have Usher and their families.

Bookings including payment of \$150 AUD should be made directly with Bronte Pyett (conferences@senses.asn.au)

Congenital Deafblind Network

Context:

People from the Congenital Db Adult Network and Staff Development Network met and created the proposed Congenital Deafblindness Network.

The first meeting of the redefined CDb network took place in Glasgow, Scotland on 21st, 22nd and 23rd of November 2006 .

It involved the following people:

Gill Morbey from Sense Scotland

Dominique Spriet from France

Pilar Gomez from Once, Spain

Knut Johansen from the Andebu Deafblind Centre in Norway

Evabritt Andreassen from Deafblind Centre, Bergen, Norway

Mary Foster from Sense (West) UK.

Definition:

In the context of this network, our understanding of congenital deafblindness include those who have a combined congenital vision and hearing disability that is present before the acquisition of language.

Aim

- To understand the uniqueness of congenital deafblindness and its implications.

In the first instance the network had decided to address this aim by:

- Enhancing staff performance in order to improve mutual understanding in contact with the person with congenital deafblindness.
- Identification and understanding of the characteristics of good practice

What do we going to do and how are we going to do this?

Our target group is staff in daily contact with the congenitally deafblind person and, so, we are planning to consult and work in partnership with this key group of staff and will meet again in May 2007 to take this work forward.

Are you interested?

Contact Dominique Spriet on spriet.dominique@wanadoo.fr

Rubella Network

Nancy O'Donnell

Background and purpose of the Rubella Network

The purpose of this network is to provide information and resources to individuals who are deafblind from congenital rubella syndrome, their families and the professionals who serve them. Although rubella is being eliminated in many parts of the world through stronger immunization efforts, children and adults with CRS continue to experience health issues related to this virus. The

number of professionals, worldwide, with experience in working with this population is quite small, yet the needs of individuals with CRS are quite diverse and complex.

Recognizing this, in March 2005, the Helen Keller National Center for Deaf-Blind Youths and Adults hosted an international symposium at its headquarters in NY focusing on the current status of rubella and CRS. As a result of this meeting, participants agreed that there was a need for ongoing information and networking. To that end, this DBI network was established.

DBI members may support and benefit from this network in the following ways:

- 1) Join a listserv for individuals with CRS, their families and professionals to discuss day-to-day issues related to CRS. This listserv is known as the "Discussion List for Congenital Rubella Syndrome – HKNC_RUBELLA." You may join this list by either sending an email to me, Nancy O'Donnell, at HKNCNOD@aol.com or by signing up via the DB-LINK website: http://tr.wou.edu/CGI-BIN/WA.EXE?A0=HKNC_RUBELLA
- 2) Join a listserv exclusively for researchers and medical personnel that serves as an international resource on CRS. You may join this list by sending an email to me, Nancy O'Donnell, at HKNCNOD@aol.com
- 3) Add your name to a database of individuals who are willing to be international resources. We encourage participation from all fields, including health care (especially specialists in areas such as endocrinology, neurology, cardiology, mental health, pharmacology, ophthalmology, audiology, pediatrics and gerontology, to name a few.), vocational rehabilitation, social work, etc. Again, you may contact me with your questions or info.
- 4) We would like to use the DBI website to establish links to agencies, organizations, resources and articles about CRS. We would also like to include information in a multitude of languages. If you have articles/info on CRS in any language, please send them to me. I would like to request a copy of the article in English, if possible, so that we can verify the information and/or links.
- 5) We have applied to have our first network meeting at the international conference in September. I am looking forward to making new connections and re-establishing old ones. If you have specific topics you would like addressed during this meeting, please e-mail me.

Links for our webpage:

Helen Keller National Center for Deaf-Blind Youths and Adults

<http://www.hknc.org/Rubella.htm>

Centers for Disease Control and Prevention

www.cdc.gov

Canadian Deaf-Blind and Rubella Association Rubella Survey

<http://www.cdbra.ca/show.do?p=rubellaNews>

Pan American Health Organization

<http://www.cdbra.ca/show.do?p=rubellaNews>

World Health Organization

<http://www.who.int/immunization/topics/rubella/en/index.html>

A date for your diary

Listen to Me – 4

Scotland between 22nd-27th August 2008

We will shortly be posting information about the draft programme and the cost on the Dbl website. For more details contact

info@sensescotland.org.uk

EDbN News

European Policy Group

In 2004 EDbN successfully led a campaign to get the adoption of a Written Declaration on the needs of deafblind people in the European Parliament. Following on from that we have been trying to raise the profile of deafblindness in Europe and make sure that the needs of deafblind people are included in European policy making work. To achieve this second aim EDbN needs to be able to respond to consultations and committee work being carried out by the European Commission. At the moment I am doing as much of this work as possible at Sense. However, I am often finding that I don't have all the knowledge needed because the consultations cover such a wide range of subjects and I am in only one of the twenty seven Member States of the European Union.

To try and solve this problem Sense hosted an EDbN meeting in March 2007 of people from around Europe who can contribute to the European policy making process. This group is being called the 'Experts Group' because the people involved can all offer different expertise.

The group includes deafblind people, parents and professionals who have the knowledge we need and who are interested in sharing that knowledge. They are people who want to make sure that policy making in the European Union includes the needs of deafblind people. Seven people attended the initial meeting at Sense but there is potential for the group to grow if knowledge on other subjects is needed in the future.

The group will advise EDbN on specific issues and respond to requests for ideas and information relating to European policy work but I will continue to send information and requests to everyone on the EDbN mailing list.

Lucy Drescher

CHARGE Syndrome

It has been difficult to plan a meeting of the CHARGE Syndrome Network at the Perth World Conference due to continuing uncertainty about who would be attending. Although I will not be there I now know that Madelene Rich and Rob

Last, both from Victoria, Australia, will be attending and presenting. Madelene has a son with CHARGE, and Rob has many years experience in working with children with CHARGE and their families. Both are very active in the Australasian CHARGE Syndrome Association. In addition to making two joint presentations with Madelene, Rob will be presenting his film compilation of several children with CHARGE which contains footage showing their development over the past 21 years. Meanwhile, most of the 'buzz' in the field is focussed on the 8th International CHARGE Syndrome Conference that will take place in Costa Mesa, California on July 27th-29th. Full information can be found at www.chargesyndrome.org

David Brown

Interpreters Development Network

Hello Everyone!

This network has only just started, so there isn't much news to tell about the things we have done in the past.

We started at the 6th Dbl Conference in Slovakia last summer and though we are new we certainly do have plans for the future!

The Interpreter Network hopes to bring interpreters for the deafblind and deafblind people themselves from various countries closer together to share information and materials. Deafblind people are very welcome because they can also share information and materials. We are aware that not all countries are equally advanced. For example, there is an issue about developing a system of paid interpreters and how to get this up and running. So we want to share ideas and answer questions together.

We will mainly communicate by email and if the possibility arises we would like to organise a seminar about interpreting for deafblind people. Also we want to inform everyone about our group and what we are doing through our column in Dbl Review. But we are also looking for members to express an interest and if you would like to keep informed through an e-mailing list, please let me know you!

Mail me at:

mirjam.leusink@planet.nl

Kind regards,

Mirjam Leusink

Chairperson for ID Network

MDVI Euronet

The "GRUNDTVIG PROJECT" in Tullangsskolen and Ekeskolen visitors

Tullängsskolan, and the secondary school for multihandicapped deaf and hard of hearing students together with Ekeskolan, a Resource Center for the blind and visually handicapped students have worked together on a project and now these schools have had an International visit. The purpose of the project is to investigate what opportunities there are for young multi-handicapped people to get a job or a daily activity when they leave school.

The visitors were members of a "Socrates-Grundtvig 2 Project" and the participating countries besides Sweden are Spain, Italy, the Czech Republic, Germany, Iceland, Eire, Denmark and Finland.

The meeting began in Tullängsskolan, where the visitors spent 2 days looking at the school and learning about the aesthetic work and the Arts Programmes provided there.

After that the group members moved over to Ekeskolan for further discussions. They could also try different activities such as clay sculpting, stone polishing and wood work.

The members of the project told each other the good examples from their own schools and they discussed "lifelong learning" and what kind of skills we practise at school in order to give the students the best chances when they leave.

The meeting was very rewarding. The next meeting will take place in Olomouc in the Czech Republic.

Employment Network

Seija Troyano tries out a new employment project

Recently, at the end of March, I finished a special project which I started in June 2005. It is a project I decided to take part in personally and see it through to find out which kind of tools it offers for disabled people with professional education/occupational training already. These are people who want to work but find it difficult to get job in the open labour market for some reason. Before that, I had heard and read about many projects that come and go, in our country and in the field deafblindness but began to question whether there is anything that comes out of them that are tools we can work with.

Because of my interest in the project, before I started, I considered why it is difficult for disabled people to find a job.

I spent most of my time discussing with the project leader about situations that are hard to crack.

The society and community around us are simply just not used to the idea of different people working different ways –ways that differ from "normal" and require some extra effort to make them "work".

If you work with a colleague like you, it is normal to help each other. You are equal, too. "Attitude" is your very personal tool. Many people tend to use it to ignore things they do not want to handle or face. How short-sighted, I'd say! When you are looking for a job, far too often you hear the polite answer like." an excellent idea, but where do we get the money for that...?"

The right to be an individual

We must stick to our rights to work and be individual with our skills. But before we can achieve our rights, the provision of law must come first, I think! I see the situation much the same as when women had to fight for their right to vote or when black people had to fight for their freedom in the past history! Thanks to the modern technology, many disabled as well as deafblind people today can profit by having a computer. It's a very important aid to work with. We have many deafblind people with a good education, even at university level and degrees. What are they doing in our modern society today? It is high time for decision makers to wake up! And it is not enough if they wake up in one country or town, it must happen everywhere and in every part of the civilised world.

Finally – what happened to me after the project?

By surprise, from the start of this year I found myself employed in three different fields which together means I have a job in a very modern and new way!

During my project I took part in some meetings where I got up-to-date information about things you need to know if you wish to be self-employed. To be self-employed sounds good – ideal – for many disabled with skills and opportunity to work at home. However, all those papers, taxes and other documents required can worry and discourage your enthusiasm quickly. I was no exception! The project leader then suggested to me that I create my job by collecting “the pieces” together from my usual work as a freelance. The “carrot” offered with it was the salary to be paid for the first six months (and then six more months if needed) to the people who employ me.

The solution however has two sides with plus and minus points in it. I find that I am now working longer for a slightly larger salary, but some of the support I received before toward my pension is not longer there. This is not the best solution for me but I am determined to see what happens when I finish my first six months and then another six more months!

Thinking positively I can now open new doors easily by offering my know-how to those I work with. They need not pay me themselves as the money for my salary comes from the project mentioned. So far I have not been short of work and I have enjoyed meeting new people with new challenges.

I have also learnt how important it is to use your own initiative!

In a way I can now almost imagine myself as self-employed – understanding much more of what it would be like! Much of my work I can do at home working with a computer. I can also plan my time-table to suit my own best way of working. At times I even work at midnight! If my brains do not want to work, I go out for a long walk and the ideas start to flow again! This just makes me wonder how people normally work if they just sit at their room from 8am to 4pm.

Well, with my work at city council, which I talked about in the last edition, I am full employed!

However, what I am after are new tools to employ others, too, not only myself!

Man's best friend

At Ali Hope Foundation they know a dog can make a huge difference in the

world of silence and darkness!

Thamara Meirovich, the Director of Ali Hope Foundation who is deaf with Usher Syndrome, type 1, fully understands the needs of people like her She has studied and is a qualified dog trainer in Israel and has already trained dogs. Now, together with Tracy, who is deaf, and 5 other people, they have started this Foundation as there isn't much support for the deaf and deafblind. Thamara takes up the story. "We are hoping that Ali Hope Foundation will aid this community in special ways.

The situation in Israel for the deaf and deafblind is not easy. Our goals are to aid these communities.

Our first goal is to train dogs to alert people to important sounds. Consider for a moment and imagine if you were deaf or deafblind and had no idea that the war siren had gone off. How would you know that you needed to run to the bomb shelter?

There are over 10,000 deaf people in Israel, and there is no organisation set up to train dogs for them. Some deaf and deafblind people live alone and have no idea what is happening around them. Specially-trained dogs act as ears for those who can't hear and alert them to take action.

Our Goal

Our goal is to improve the independence and well-being of deaf and deafblind Israelis through the provision of specially-trained Hearing Dogs.

Most deaf or deafblind people at some stage face the reality of missing important sounds... crucial, possibly life-saving warnings that many hearing people take for granted. Mainly those individuals who live alone or in a place where there are no hearing people, it can be important that they be alerted to certain happenings e.g. a knock at the door, an alarm; the sound of a prowler. Our dogs give deaf people security and they know they have a dog that can be trusted for their safety.

Ali Hope trained hearing dogs will offer a practical alternative for many deaf people and can be constant companions capable of responding to many different situations and alerting their deaf owners to important sounds. Also providing emotional and social benefits through their companionship and encouragement of more contact with public society as people will SEE that the person is deaf as deafness is an unseen handicap and they will get more practical help from people in public. The dog will also perform a protection role as well.

The dogs are specially trained to assist by alerting deaf and deafblind people to become aware of certain needed daily sounds they miss out on both at home and in public places.

Dogs will be trained and placed with people who are deaf and deafblind. The deafblind will not feel alone, they will be alerted to sounds within the home and be led carefully to the source of the sound. The deafblind person will be able to go out for air just outside their home and enjoy the company of their "sound alerting" dog. These dogs will not be like guide dogs for the blind, to lead them in public.

The deaf person who has the hearing dog can choose the sounds they want their puppy to be trained to respond to. The puppy can then be trained by the

Foundation to alert them by “pawing”/ touch and lead them to a variety of important daily sounds they don’t hear.

The puppy can then alert them at home to:

- Doorbell ringing/knocking on the door
- Fax ringing
- Mobile text message/beeper beeps
- Child calling “mommy” (or other name eg. daddy, granny etc)
- Family member or other calling the name of the dog’s partner
- Alarm clock ringing
- Wind up minute timer, oven or microwave timer going off
- Water boiling
- Baby crying
- War siren alert

Also with sounds away from home:

- Mobile text message/beeper beeps
- Fax tone at work
- Name of dog’s partner if co-worker, friend or family member calls out that name
- War siren alert

Would Dbl members like to know more about our work? We would like to hear from you!

For more information about Ali Hope Foundation visit our website www.alihope.com or email me at t_t_hope@yahoo.com or fax +972 2 673 3029 or mail me at P.O. Box 32196, Jerusalem, 91000, ISRAEL

What a development!

Lone Poggioni reports on how the expanding work in Nepal has made a big difference for one little boy!

Some background

In November 2004 I went to Kathmandu in Nepal representing the Danish Parents Organisation for Congenitally Deafblind People. My job was to see if any help for deafblind children was needed. And there was indeed a great need, because there was a lack of focus on the specific disability, deafblindness, and the absence of an overall education program for deafblind children.

Manoi and his family

At that time I visit Manoi and his family for the first time. He lived up the mountains with his nice – but very poor family – consisting of grandparents, parents, two brothers and a sister.

My first acquaintance with this 7 years old deafblind boy really touched my heart, because he looked so, so thin and was drooling saliva all the time. He preferred to sit on your lap, could only crawl and slept curled up in a ball. This

was probably because his bones were weak. He was unable to hold anything, and so he had to be fed and he needed help with bathing and using the potty, which he disliked and avoided. He had headlice and was dirty as a result. He didn't have many friends because he was always fighting.

With financial support from the Danish Government Inger Roedbroe, Bente Ramsing and I started in November 2005 a Model Project for Deafblind Children in Kathmandu composed of a School for Deafblind Children, a residential setting and two fieldworkers. Manoi was one of the first children in the School, which now has 6 deafblind children.

The staff were in-service trained among others in:

- Deafblindness, which included how to teach the staff how to communicate with deafblind children.
- Individual evaluation programmes, which includes all the children's files together with the primary teacher, talking about how the child is using the senses to find the best learning style for each child.

With the knowledge, patience and love from the staff Manoi's development started very fast!

In fact, when we went back in July 2006 Manoi was already walking unaided – it touched us all deeply!

Half a year later in February 2007 Manoi is now able:

- To indicate when he wants to go to the toilet, and he goes independently by holding the wall
- To wear his clothes himself
- To hold his toys and play musical instruments
- To understand when we indicate him to go to the play ground
- To wear his shoes when we take him to the shoe rack
- To play swing alone if we make him touch the swing

And he:

- remains happy all the time but shows anger when he is not well
- recognizes his teacher and responds when his name is called out
- is very obedient now
- undresses for his bath happily and he is much cleaner now
- indicates by pulling hands if he wants to go out
- uses hearing aids properly
- brings his chair while eating and cleans his plate himself
- does all the activities at school happily

Manoi has really confirmed our thesis, that a deafblind person has potential if professional services are provided.

But first of all Manoi is now a lovely little boy who brings happiness to his family and the whole Deafblind Unit. The sky is the limit in terms of development in the future!

CHARGE syndrome: dual sensory impairment, cognitive development and anxiety

Psychologists, Charlotte Reau, Corinne Blouin and Christine Tap conclude their series of three articles on their research with children with CHARGE. In

this technical article they report their first clinical observations.

About the research

Its aim was to discover the links between sensory impairments, cognitive development and anxiety. Over a period of 3 to 4 years 9 children with CHARGE were compared with other deafblind children. The children were aged between 8 and 20 years old and there were 5 boys and 4 girls. Author's note: only one young person is currently receiving drugs treatment for anxiety reduction.

First clinical observations

The expression of language

- infra linguistic dimension (no coded communication, therefore body using communication)
- language not included in a dialogue: expression like "for oneself". They are emissions of exteriorized inner language.
- Language registered in the oral metaphor examination or LSF

The majority of the observed children are in an infra linguistic dimension. The things that are expressed, are said, using the body. They are children much more receptive to anguish than others. The anguish is observed here like a feeling. These children express it but in a very old fashioned way, because the language is lacking or is extremely poor.

We postulate that anguish exists for everybody, since it is an affect. We all are thus subjects to the automatic anguish, being itself deeply related to impulses.

What do we mean by "anguish" for this study?

Anguish (which comes from Latin "angustia" which means "narrowness and tightened place") is a physical and psychic faintness born from one's feeling of the eminence of a danger characterised by a diffuse fear which can go from concern to panic and which is accompanied by psychomotor vegetative demonstrations. It is a feeling and a state of displeasure. It is a reaction, compared to a danger not clearly identified, to which one cannot prepare to. The origin of the anguish is in the original trauma and the anguish is the repetition of this trauma.

Understanding what we mean by types of anguish

In the child

- Since birth we have to have automatic anguish... It is a state of distress of the small baby
- Anguish of the 8th month
- Anguish of the loss of objects: it is a danger felt by the child because of the absence of autonomy.

In the adult

This anguish of loss of objects felt by the child grows in the adult into:

- “castration distress” in neurotic people
- “parcelling out distress” in the psychotic (but also of collapse, explosion, of self-mutilation, existential distresses)
- loss of object distress in the personality limit states, i.e. of the personalities oscillating between mechanisms of defenses of the neurotic structures and psychotics.

We will deal here with the “loss of objects” anguish for these children, from the point of view of normal children. Indeed, this anguish is a structuring one as it facilitates the installation of separation and individualization processes. This loss of objects factor of anguish can be dangerous for the little baby, when experiencing the absence of his mother. This is what makes it dive in a psychological distress due to his instinctive need that can be appeased only by his mother.

The child is stripped at the start of its instinctual requirements, because it is unable to understand and appease them because of its physiological immaturity. This leads to signs of distress that only the presence of the mother can alleviate. The mother does not behave a usual mother would, but comes to calm the impulses.

Separation and medical intervention for mother and child

Because of early and prolonged medical intervention after the birth of the children suffering of this syndrome, the mother is, from the beginning, dispossessed of the capacity to decide moments of separation or absence from her child. These early times with the child cannot be as she would wish. Moreover she has an important culpability and an anguish because the child's life is at risk. For the same reasons, the child is deprived of its mother and of her care. What happens to the child is not foreseeable and this environment, which is often painful, increases the anguish the child experiences.

So the anguish associated with a loss of object is, as we can see, worsened by:

- unpredictability of the environment (whereas early education aims to set up as quickly as possible a system in order to reassure the child)
- anguish of the parents and family facing to the risk to the child's life
- lack of a close physical relationship with the mother, but also of olfactory, auditory and visual relations because of the handicap of the child.

This unquestionably creates damage in the construction of personality, the communication and future relations of the child with the environment.

It is however possible for the child to be in hospital with plenty of care being lavished on it and not feel abandoned. On the other hand all these children are very sensitive particularly when people change around them, and they are unfamiliar with them. One can therefore think that they have developed, on the other hand, an “insecure” relationship with people, due to these hospitalizations.

We have some serious, practical thinking to do about how to support the early mother/child relations by accompanying more families, children and professionals at the times of postnatal hospital admission which usually

happen with this syndrome.

All things that help with the foundations of relationship building are thus made difficult by the disability:

- Holding : the care becomes more like nursing and rather than comfort or cuddle
- Food: often problematic because of crossroads ORL and sometimes with gastrostomy, whereas it is normally a moment of shared pleasure
- Fitting in: made difficult because of the facial morphological aspect of the child, which can make it difficult to be accepted and integrated in the family
- Language: as the child is very quickly diagnosed as having a hearing impairment, people do not speak to him any more, and when they do it is often very calculated, and lacks spontaneity and naturalness
- Family and friendly support: often absent or disappearing because of the complex disability of the child.

All this creates a difficulty for the parents to find their place and control, a feeling of impotence with respect of the child's life, and sometimes, a feeling of incompetence to understand or decode signals emitted by their child.

From the point of view of the child

Out of all this, the child only perceives feelings which it cannot understand. It feels that there is a constant agitation/change around it, that because of that, demands the permanent attention of the adult as mediator of the relationship. They are children who invest enormously in one of the senses and particularly the tactile one.

They are very permeable to anguish, have strong relationship with the body and the feelings of the others, much more than with their one feeling.

Tactile sensitivity structured in place of spoken language?

One could make the hypothesis that these children developed a tactile sensitivity as structuring in place of spoken language. It is as if they had learned how to decode and understand the people touching them.

Since the child's birth all the dimensions like naturalness, spontaneity, pleasure, play, all that is "free" in the relationship disappear, replaced by the care routines that ensure their life. Later the children do not play, do not stroll, they are devoted to a training programme to ensure they learn "step by step" (school, autonomy, walk...)

Could this be contributing to their lack of initiative in relationships and communication. There is no possible free expression, except with the support of image linking with a computer, but this is still mediation using the adult and a machine. In addition, it must be noted that they are children, who, in spite of their level, do not express themselves, as though they had not had access to the pleasure relationships and self expression.

Conclusion

In spite of their difficult beginnings, the children we have studied are full of energy, always in search for human relations and to learn more!.

We must, as professionals continue our efforts and our research on this syndrome in order to adapt our educational attitudes to fit their needs and actions and, as a result, to improve our modes of communication and of our ways of working alongside them.

Is CHARGE a name with negative connotations?

Christine Tap put forward some ideas about the connotations of the name CHARGE in her piece in the magazine last June called “And what is the impact of this acronym...CHARGE? In this she proposed that the label of CHARGE, in France, links the condition with an individual’s identity in a negative way and that it functions as a stigma. She opened this up for discussion and welcomed responses. Simon Howard, who is parent of a child who has CHARGE and Joff McGill responded, with the help of the CHARGE listserv...

The article generated the most responses on the CHARGE listserv. A lively, at times humorous and heated discussion, involving individuals with the condition, parents and professionals, suggests that most people with CHARGE and their families do not agree. They acknowledged, however, the importance of challenging negative language and negative views about an individual that are solely based on their medical condition.

Here are some of their observations

“the word CHARGE is not a stigma, it is a name to the medical condition that I have. It’s part of me that I’ve accepted long ago.

Young adult with CHARGE

“I have to say the thing that will cause anyone to have a negative self image, feel guilt....is having constant negative feedback about them and their condition. Let’s call it Fred and it will have all of the above if a child is brought up to feel or to believe these things are what they are.

Parent

Christine has postulated the idea that Charge in French could mean “a burden”. Firstly those on the listserv rejected the notion of a burden. They came up with many alternative, positive, empowering meanings of the word CHARGE including ‘charging ahead’, ‘taking charge of disabilities’, ‘charging through life’, and ‘being in charge’. Very few people recognised or used the word with the meaning ‘people we are responsible for’.

“How can you say that a child is a “burden”?”

Parent

In French, the word ‘charge’ does mean “loaded or burdened” but can also mean expense, cost, custody, employment etc. The meaning though should not matter since CHARGE is an acronym, not a word, in this context. It is useful to make an acronym that is easy to say as it acts as “shorthand” but there is a danger in imposing meanings.

It was acknowledged that there may be an issue with ‘signs’ that convey negative meanings of the word CHARGE, and that perhaps more positive versions could be suggested – for example, the CHARGE Syndrome Foundation have a sub committee of young adults to consider what the ASL sign for CHARGE should be.

Labels can be useful and they can be negative. Members of the listserv acknowledged that having a label such as CHARGE could be negative, but only in that any name has the chance of carrying some stigma. CHARGE is no different in this respect to deafblind, cerebral palsy, downs syndrome etc.

“Well, I unfortunately think she is right that labelling someone with a condition does create a stigma. But whether you call it “CHARGE” or “RAGCHE” or “Uncle Mickey’s Syndrome” doesn’t change the fact that the name – any name – will in time come to carry the stigma of the genetic disorder.

Parent and professional

Overwhelmingly people highlighted how useful the label can be. Some believed the label gives information and provides access to resources and medical care; that it does not define an individual, but that it does give individuals and those around them a framework for what to expect. Others went further and suggested that it allows them to express their identity; that the condition and its label is a part of them that they came to accept. It was suggested that the name gets across the nature of CHARGE, ‘a set of challenges whose sum exceeds their parts’.

“The name of the syndrome just gives some ideas about the challenges the child may face...people need to realise that different does not mean less than.

Professional

“Labels are for items not people.

Parent

It was argued that names and labels become negative because the world outside only sees different as suggesting ‘better’ or ‘worse’; we all need to learn to value different as just being different. One person suggested that the word ‘syndrome’ does get more negative reactions than the word ‘association’. Others highlighted the importance of people remaining ‘people first’; that referring to ‘CHARGE children’ or ‘CHARGErs’ ruffles more feathers than ‘children with CHARGE’. Individuals want to be able to express their own identity, not be defined by a condition.

***“J is a child with CHARGE.
J is not her condition.***

Parent

Finally, practical difficulties were highlighted. Not only is the name too well established, but attempts have been made to change it in the past. Medical convention suggests that syndromes are named after those that identified them, so some medics tried to suggest that CHARGE was changed to ‘Hall-Hittner Syndrome’ – it never caught on!

There is recognition that CHARGE when translated as a word into the French language has an unfortunate outcome. However while being careful about the labels we use we also have to recognise that labels can be useful. It should always be about being a child, a person, an individual who is unique.

Editor’s note: Comments from the listserv are not representative of European language users.

The 10th European Deafblind Holiday

Søgne Conference Centre, Søgne, Norway,
From Monday 6th to Sunday 12th August 2007

Hosted by the Norwegian Association of the Deafblind (FNDB)

Dear friends,

We hereby confirm that the 10th European Deafblind Holiday will be arranged in Norway! Søgne is located at the south coast of Norway, about 16 km from Kristiansand. This is a very beautiful part of Norway, lying close to the sea with great opportunities to go swimming and fishing. Søgne has 9.400 inhabitants and is a very popular tourist place during the summer.

If you want to see if any places are still available please contact FNDB by e-mail fndbadm@online.no or by post, phone or fax to our address and number:

The Norwegian Association of the Deafblind (FNDB)

Postboks 5922 Majorstua, 0308 Oslo, Norway

E-mail: fndbadm@online.no

Telephone: + 47 22 93 33 50

Telefax: +47 22 93 33 51

We look forward to seeing you in Norway.

Yours sincerely,

The Norwegian Association of the Deafblind

Geir Jensen

President

University of Groningen, the Netherlands

Masters Programme, Educational Sciences Section

MSc Communication and Congenital Deafblindness

Description of the programme:

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

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

This innovative European Master's programme is based on and inspired by the work of the Dbl ECN1 .

Contents

We will explore the possibilities of a dialogical approach to communicative development including: Dialogicity of mind: intersubjectivity-subjectivity; Conversational practice: tactile approach; Communicative intentionality; Joint attention; Spontaneous gestures: meaning potential; Spontaneous utterances: meaning potential; Referential gestures: mimetic, iconic and pointing; Narrative frames; Negotiation of shared meaning.

The students will learn how to apply this conceptual framework in the context

of assessment, intervention and research.

Structure of the Curriculum

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

This is made up of:

- specialised theoretical themes, including the study of literature (10 EC)
- a project, that is a research or clinical-based thesis (45 EC's).
- a reflective essay linking project work to overall theories and models (5 EC's).

Structure of the programme

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

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

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

In May, students write the reflective essay.

All work has to be finished by 31st August

For more about Admission Requirements, fees and facilities

DbI European Communication Network

Curriculum coordinator: Dr. Marleen Janssen

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

Expertise, Sint-Michielsgestel, The Netherlands.

Australia

Mike Steer

Australian Deafblind Council welcomes the Prain Report

The Prain Report was prepared by Meredith Prain on behalf of the Australian DeafBlind Council (ADBC). It was funded by the Australian Commonwealth Government's Department of Family, Community Services and Indigenous Affairs with additional financial assistance from Able Australia Services (previously The Deafblind Association) and numerous members of the Deafblind Community who volunteered to assist Ms Prain at their own cost. The project was intended to update the results of Mary Ward's 1994 Report and was to include demographic information, an outline of current services, a discussion on service needs and an action plan for people with deafblindness in Australia. Concern has remained high amongst people with deafblindness, family members, and professionals at the lack of action and inadequacy of services for people with deafblindness since the Ward Report was produced. In July 2001 a National Forum on Deafblindness was held in Sydney funded by the Commonwealth Office of Disability with the aim of presenting its results to the National Disability Advisory Council (NDAC). The major result of this event was deep concern at the situation of people with deafblindness in Australia. The National Forum finally led to a meeting in 2004 with the Chair and Deputy Chair of NDAC and with the Assistant Director of the Office of Disability. As a result of this meeting \$15,000 was made available in June 2005 by the Commonwealth Government to ADBC for a research project. After appointment of a Steering Committee and Reference Group and preparation of the terms of Reference, the Consultant, Meredith Prain, was appointed. She commenced in December 2005.

The ADBC's definition of Deafblindness was used in the Report:-

"Deafblindness is described as a unique and isolating sensory disability resulting from the combination of both a hearing and vision loss or impairment which significantly affects communication, socialization, mobility and daily living".

The study estimated that there were 3984 people with deafblindness in Australia, based on recognised norms for other developed countries. Due to the difficulty in identifying people with deafblindness in the community, only 682 were identified by the study, highlighting the poor quality of statistics held by all Government Departments and the Bureau of Statistics on people with deafblindness. Most people who were identified were in the 19 to 65 year old age bracket. While a wide range of causes of deafblindness were identified the largest cause was genetic/syndrome-related. The report recognised that few

people over 65 years of age were identified and if they had been, they would have formed a much more significant group. It was recommended that a register of DeafBlind people be set up.

Services for people with deafblindness were found to be highly inadequate in all Australian states. However, more appropriate and relevant services were found in those States with deafblindness – specific services -for example, in Victoria and Western Australia.

Further it was recognised that agencies providing services for people with a single sensory impairment are poorly equipped to provide appropriate services to people with deafblindness. This is due to their inability to support people with deafblindness across a wide range of needs, leading to extreme isolation of the people they are trying to support and with an inability to help them enter and use the local community and its facilities.

Also, most people with deafblindness require one-to-one support due to the individual nature of their communication and mobility requirements, thus needing specialist skilled support workers who are often not available, leaving these people prisoners in their own homes.

People with deafblindness form a very diverse group due to the varying degrees of their vision and hearing impairments, plus possible additional disabilities. This diversity leads to need for a wide range of communication methods including speech, oral/aural communication, various forms of sign language including tactile, deafblind fingerspelling, alternative and augmentative communication and print/Braille.

The Prain study found few people who were Aboriginal or Torres Strait Islanders or from a non-English speaking background and it was recognised that the number found was not truly representative of these groups.

While the number of people who were identified with deafblindness made population trends difficult to discern, it is widely recognised that Congenital Rubella Syndrome is reducing and being replaced by a range of syndromes and complex medical conditions. However, with the overall aging of the population and the increasing numbers of people who fit the functional definition of deafblindness, the number of people with deafblindness is gradually increasing.

The report noted that while some accommodation is available for people with deafblindness in Victoria, New South Wales, South Australia and Western Australia, vacancies rarely occur and they are generally for people with additional disabilities. This puts significant pressure on parents. Some young deafblind adults live in hospitals or nursing homes. This is an area of great concern. Further well-trained staff are needed for any future homes.

While in all States the educational needs of people with deafblindness are met to some extent, there are issues in some instances where services are provided by experts in vision or hearing impairment but not in both. This is especially a problem with visiting teachers in country areas where travel is also an issue.

Training for people with deafblindness exists in four States, mainly in communication and daily living skills and in all States for orientation and mobility training through the Guide Dog Associations. The only national program of any type for people with deafblindness is the Link computer training program operating from Victoria. It provides funding for transport and accommodation as well as follow-up support for people in their own States. It is

funded through non-recurrent trust funds and limited State support in Victoria. The only service in Australia that has the skilled staff to genuinely assist people with deafblindness to gain open employment is Melbourne-based SensWide although the number of people it assists each year is quite small. Other services that can theoretically assist lack the skilled staff to be of assistance. Day services have similar issues although Able Australia Services operates two services in Melbourne that include people with deafblindness. These two services employ appropriately skilled staff.

Case Management is provided to 50 people in Victoria and some 8 to 10 people in NSW. South Australia provides a complex case management service for people with sensory impairments including deafblindness.

Funded recreation programs, that include volunteers, operate in Victoria, South Australia and Western Australia. Programs run entirely by volunteers operate in NSW and Queensland. Victoria also has a number of clubs formed by people with deafblindness including The Vision Hearing Support Club and the Victorian Usher and Deafblind Club.

In all States, except Victoria and Western Australia, the only respite services available to people with deafblindness are the generic services. The services generally have no experience with deafblind people and are totally lacking in staff with appropriate skills.

Community Outreach programs exist only in Victoria and Western Australia with a service for two people in South Australia. These services, however, lack the flexibility desired and people in country areas are severely disadvantaged. There is currently a deafblind interpreting component in interpreter training courses in Victoria and Western Australia and relay interpreter courses in Victoria, NSW and South Australia. Queensland has only two interpreters with experience in deafblindness and Tasmania has none. ADBC has guidelines for interpreting for people who are deafblind. The National Auslan Interpreter Booking Service provides interpreters for medical appointments although experienced interpreters in many areas are few. This is especially true for interpreters for people who also have an intellectual disability.

Few people working in the field have formal qualifications in the area. The only recognised accredited training that includes deafblindness is teacher training for working with children conducted by the Renwick Centre in Sydney. Able Australia Services, DeafBlind Services (NSW) and Senses Foundation provide in-house staff training. In 1994, Mary Ward highlighted this as a problem and recommended that it be treated with urgency.

There is significant knowledge in Australia and overseas about deafblindness. However, without the assistance of a central information service or access to adaptive technology many people with deafblindness are unable to use this information. This is also true of their families who in consequence feel very isolated. This is an urgent issue and the Prain Report recommended that ADBC should receive Commonwealth Government funding for an Information and Referral Service.

The study found very few people over 65 with deafblindness. Overseas studies have shown this not to be the case and that not only is there a large number in this elder group but it is growing. Funding of deafblind services is required to address this issue.

Other issues raised in the report are the lack of a funded advocacy services, awareness of deafblindness, access to transport, lack of cooperation between

services, services to rural and remote areas, examples of exemplary service models, costs of services, sources of funding and counselling. Again, in the case of the latter item, this is only available in Victoria.

The Report states "If Helen Keller were alive and living in Australia today, the services available in most States would be inadequate for her to support even a rudimentary lifestyle, let alone the famous lifestyle she led as an ambassador for her country".

This conclusion is highly disturbing to ADBC.

The Report makes 15 recommendations, the three most important of which are:

Recommendation 4. That funding be made available to maintain the national computer training service currently provided by The Link program.

Recommendation 5. That funding be made available through the Commonwealth State Territories Disability Agreement (CSTDA) for deafblindness-specific community support and interpreting.

Recommendation 9. That funding be made available for the Australian DeafBlind Council to appoint a national Information and Referral Officer.

Parents respite weekend: Western Australia

A 'Parents Respite Weekend' was held at the Rendezvous Observation City, in Perth on the 19th and 20th of August 2006. It was widely deemed a resounding success. The weekend was made possible through funding for a 'Family Leadership and Initiatives Program' generously supported by 'The Channel 7 Telethon Trust' and 'Carer's WA'. The weekend's purpose was to provide parents with a valuable break from their caring role, in an environment free from stress that encouraged relaxation, fun, education, and sharing with other carers. In consultation with parents it was decided to run workshops over the weekend covering 'Grief & Loss' and 'Siblings Issues'. It was an insightful and deeply moving experience for many of the participants, one father stating that "this is the first time in 9 years of being a father of a child with a profound disability that anyone has asked me how I felt". Other comments from the parents included:

- "Very relevant, I wish we were given the tools to deal with these issues years ago".
- "Got more from this than expected. Will help with sorting through emotions in the future"
- "Excellent. It's amazing how comfortable we all felt despite the sensitive nature of the topic and the fact that we didn't know each other".

The afternoon session was on 'Siblings Issues'. Issues covered included: concerns siblings may have, how to support siblings, family balance and the positive effects of having a sibling with a disability. Comments were all very positive and one told us, "I'm sure all families have to go through many similar problems. I felt I learnt lots from the other parents"

The parents shared a lovely lunch and a sumptuous dinner as part of the programme and to end the weekend they were all treated to a pampering session at the Vanilla Day Spa. Some of the treats included Swedish massage, facials, pedicures and manicures.

This program was designed to give parents a break from the caring role, the opportunity to meet other families, exchange experiences and acquire new information and knowledge that enables them to cope better with their particular situation. For many parents this was the first time, especially the fathers, they had an opportunity to meet with others in similar circumstances.

The Deafblind Association changes its name to Able Australia

On November 8, 2006, The Deafblind Association of Victoria launched its new name Able Australia Services! The organisation plans to remain focused on creating a community where people with deafblindness and multiple disabilities are seen, heard, respected, valued and connected.

The Hon Peter Costello, MP (Federal Treasurer) addressed over 150 people at the ACMI Building in Federation Square, Melbourne. The night of the launch was a huge success with staff, supporters, families, government representatives and people with deafblindness all having a chance to meet and celebrate the new look of the organisation. The organisation looks forward to continuing to service the deafblind community and people with multiple disabilities under its new name Able Australia Services.

The name change has taken place so that the new name focuses on the ability of the people it serves. It plans to continue to be a strongly people-focused organisation and its new name (Able Australia) celebrates everything that the people it supports are able to achieve, everything that it is able to do in supporting them and everything that the greater community can do as well. Furthermore, they are also making sure that their current name best reflects the full range of skills and services it provides. With its new name it will continue to provide and expand its services to people with deafblindness and multiple disabilities.

Able Australia Services has a number of core service departments that carry their individual titles including Able Deafblind Services; Able Lifestyle Choices (covering recreation, therapy, education and community inclusion); Able Living (Group Homes, Supported Living, Outreach and In-Home Support); Able Respite; Able Music Therapy; and Able Link (National Adaptive Computer Technology and Training Program).

More than anything, Able Australia represents and strives for all people to be able to communicate, to participate, to access resources, to reach self-fulfillment, and most importantly to be able to connect with the greater community.

www.ableaustralis.au

Good news from Senses, Western Australia

Specialist Communication Services are working on two, 12 month projects to promote information relevant to individuals who are deafblind and their families:

Usher Syndrome Support Group.

The development of the Usher Support group has begun. There are 12 people known to Senses Foundation who have Usher and we plan to meet with each person and invite their ideas on what and how we could provide the foundations for a group that provide the best information and support. We will also be providing information to associated agencies so that people with Usher, unknown to us, can find out about the support networks for people with similar needs and concerns.

Contact with Usher Syndrome groups and services in Australia, UK, Canada and US has begun and people have been very willing to help. We hope that more regular on-line and face-to-face contact will build on the friendships between people that have developed over many years, and provide a welcoming group for people new to the services of Senses Foundation.

The Deafblind International World Conference in Perth in 2007 will provide a wonderful opportunity for all of us in Australia to learn more about Usher Syndrome. We aim for the people in the Usher Support Group to be in the best position to take advantage of the conference on our doorstep.

Deafblind Training Package

SENSES has begun compiling current resources, and developing items to fill in gaps we have identified, to produce a comprehensive training package, an update of Sharon Barrey Grassick's 1997 training package. The focus will continue to be a practical understanding of the impact of deafblindness and how it affects communication, socialisation and daily living. The intended audience is direct contact staff, but much will also be useful to others, such as families. We will be using on-line and teleconferencing sessions where possible to increase information accessibility. For enquiries, please contact Robin Hamilton, Deafblind Communication Specialist, Senses Foundation.

Information from: rhamilton@senses.asn.au

Slovakia news

The parents, professionals and deafblind people had very good reason to be happy this year!

Since the year 1997 when the Association of Parents and Friends of Deafblind Children in Slovakia was founded professionals and friends worked to get the group home for the deafblind adults in Slovakia set up. They worked very hard and on 27th of February 2007 the official opening of the first group home "Lighthouse" in Zdoba – the village near Kosice in Eastern Slovakia, took place. The Lighthouse will offer the services to deafblind adults.

The aim of this project is to support the deafblind adults in their efforts to create their own lives and activities.

Janka Sarisska

Canada news

Stan Munroe reports

Intervenors, professionals, consumers and educators were treated to a very comprehensive three day conference at the Royal York Hotel in Toronto, Ontario, February 15-17, 2007. The Conference was organized by the Ontario Chapter of CDBRA and co-sponsored by CDBRA-ON and the Ontario Ministry of Community and Social Services. The theme of the conference was 'Celebrating our past, creating our future'.

The Symposium was opened by an address from the Minister of Community and Social Services (MCSS) from the Province of Ontario. This Ministry has been a long term supporter of persons with congenital deafblindness in Ontario. MCSS co-sponsorship of this event, together with their high profile attendance, reinforced their intension to improve the quality of life for those with acquired and congenital deafblindness in Ontario.

A View into the Past (part of the theme) was featured in addresses from Stan Munroe, Executive Director, CDBRA (National) and Joan MacTavish.

Stan spoke about the history of CDBRA and intervention. He indicated that to celebrate our past we must emphase the spirit that bound together the parents of the children who attended W.Ross Macdonald School (who were the nucleus of CDBRA), the teachers, other professionals etc was the philosophy of intervention. This philosophy was born and bred at WRMS through the efforts of Jacquie Treffry and John McInnes and staff that worked with them. The philosophy did not end at WRMS but it flourished beyond and continues today in all facilities and all walks of life where persons who are deafblind live and participate in society in Canada.

Joan reached further back to reflect on the history of deafblind education in Canada and of persons with this disability who made a difference. Joan reflected on her experience establishing a deafblindness service program with the Canadian National Institute for the Blind. This accomplishment followed her tenure as an Intervenor for Mae Brown, who graduated from the University of Toronto in the early 1970's. Joan is the author of BRAVO MISS BROWN, which traces Mae Brown's achievement against the odds of deafblindness. The rest of the Symposium featured an eclectic array of presentations (and presenters) all relevant to the keen audience, most who unfortunately never have the opportunity to participate in this type of professional conference.

Titles from home grown presenters included 'Compassion Fatigue – This is Not Burnout' (Nandini Farkas); 'Interpreter-Intervenor Database' (Charles Lawand); 'Development of an Assessment Tool' (Dr. Dawn Dalby).

International presenters included Dr Lauren Lieberman-USA (Research to Practice: Physical Activity and Individuals Who are Deafblind; Communication Strategies and Modification to Recreation and Fitness Activities for Adults Who are Deafblind), Mary Guest-UK (Working with Children and Adults with Usher Syndrome) and Dr. Jan van Dijk-Netherlands (What I Have Learnt in 40 Years of Practice; Challenging Behaviours).

The Symposium concluded with vendors and displays and a closing banquet. Motivational speaker, Farley Flex, one of the judges of Canadian Idol, spoke

on 'Know Thyself: Recognizing and Managing Your Talent'. For the participants and for CDBRA, several of the presentations strongly reinforced that Canada's Intervention approach continues to be the way forward and the road map for the Future in ensuring that Canadians with Deafblindness Have the Best Quality of Life. Those wanting the Proceedings can contact the CDBRA Ontario Chapter.

Scotland

International Partners

Sense Scotland were privileged in 2006 to welcome one of our international partners from Slovakia, to work alongside our care home staff within Overbridge. Janka Sarisska, came to Sense Scotland for 12 weeks last October to study our methods of communication with deafblind service users. She would then take some ideas back to Slovakia, as she will be managing her own care home for adults with dual sensory impairment. She said:

" I found the atmosphere very homely, and warm, and the staff were extremely accommodating and friendly"

Janka stated that some of our practice was different to what she was used to, from risk assessing to relationship building with service users and in particular, their families. Janka also noted that her usual approach was very much from an educational perspective; to carry that forward into one's own home, without the "rigidness" of a "timetabled" life was very refreshing and the responses from services users were enlightening.

We would like to thank Janka for her time at Overbridge, she was instrumental in setting a home environment for one particular deaf-blind service user and we look forward to meeting up with her again in the future. This work between our international partners shows that we are still learning but also that Sense Scotland has a lot to offer while still building communication strategies.

John Roxburgh, West Regional Manager – Sense Scotland

Israel

Dear friends of the Deafblind people,
Greetings from Israel. We are thankful to have contact with you and want to keep you informed of the work that is taking place in Israel. Our website is not complete yet and in the meantime we want to share this website with you and we would appreciate it if you could pass it onto others who would benefit from it, it is www.alihope.com Hopefully soon we will have it translated into other languages.

Look forwards to hearing from you, Tamara.

Tamara Meirovich

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Romania News

UK Schools Minister, Jim Knight, MP, visits Eminescu School in Bucharest

Cristiana Salomie writes to record a landmark visit

Mr. Jim Knight arrived accompanied by his educational advisors and the British Ambassador in Romania, Mr. Robin Barnett. From the Romanian side there was Mr. Dumitru Matei, State Secretary for Preschool Education, Mr. Cristian Alexandrescu, Chief Inspector for Mainstream and Special Education in Bucharest and Mr. Mircea Vlad, General Inspector – Special Needs Department. Jim Knight visited the school first and Headteacher Sanda Casapu showed him around explaining about the range of pupils and their abilities and disabilities. She discussed the importance of the school for the deafblind and multi-sensory impaired pupils and the great value the relationship with Sense International Romania had brought providing equipment and training. She introduced me to Mr. Knight and I spoke to him about how the partnership got started with the Ministry of Education through the department of Mr. Vlad. So, Mr. Vlad joined in and he provided detailed information. Mr. Knight enjoyed being with children and he seemed very eager to know about the way the children communicate and about the provisions put in place in the school and generally.

After the tour of the school, all the visitors were invited for a cup of tea in the staff room where the discussion continued on the same topic in a very pleasant way. After half an hour, Mr. Knight stood up, thanked everyone for the hospitality expressing his admiration for the school's physical conditions and the "excellent" way in which children are educated. He apologized for the fact that he had to go and left within a few seconds – which is a very British way! He also made the remark that the children he met seemed very happy, communicating very well with their teachers.

Apart from the honour of being visited by the Minister of schools in UK, the event has represented a good opportunity for Sanda and her staff to demonstrate their excellent progress to other senior members of the Romanian education

authorities. These are all colleagues of Mr Vlad, who has personally championed this work right from the start.”

Poland

Usher syndrome in Eastern Europe

Plans to hold a workshop on Usher syndrome for key professionals in Eastern Europe have moved forward one step.

In March, Marylin Kilsby and I went to Poland and met Dr Hanna Siedlecka, an audiologist working in Warsaw. Hanna had kindly arranged for us to meet the head of the Polish Deafblind Association, Grzegorz Koslowski, to discuss the plan to hold an Usher workshop.

During the morning, we had the opportunity to hear about the Polish Deafblind Association which was founded in 1991, under the auspices of the Polish Blind Union. Currently they are aware of 2,000 deafblind people throughout Poland. Their Association is keen to develop links with other organisations such as Sense who have already developed strategies for working with deafblind people.

The Polish Deafblind Association is interested in looking at legislation which defines and upholds the rights of deafblind people. In connection with this, we met Jane Cordell who is First Secretary at the British Embassy in Warsaw. Jane herself became deaf in her twenties and uses a lip speaker, together with sign supported English, to communicate in meetings. She is interested in legislation and supporting the Polish Deafblind Association in its objectives. We were pleased to hear that Access to Work, which provides support for employees with disabilities in the UK, allows for the communication support needed by a deaf person to carry out her work at the British Embassy. We had a useful time with Grzegorz, Malgozata Ksiazek and colleagues and, with Hanna's help, we now have an outline programme and some actions for us all to follow up on. One of the problems we must sort out will be finding funds for interpreting and translation.

We hope that the Usher Workshop will attract professionals from the Ukraine, Slovakia and perhaps Lithuania, as well as from Poland. The Workshop is aimed at key workers who are interested in developing skills and good practice in their work with children and adults with all forms of Usher syndrome.

For further information, please contact mary.guest@sense.org.uk

Mary Guest

Jacquelyn A. McInnes (nee Treffry)

CDBRA in Canada mourns the loss of a valued friend and mentor and inspiration around the world

It was with deep sorrow that we learned of the death of Jacquelyn A. McInnes (nee: Treffry) in early March, 2007 after a long illness bravely borne.

Jacquie was one of the pioneers in the education of children who were deafblind. Her affiliation in this field began in 1968, when she attended the Perkins School for the Blind in the USA to learn more about deafblind education. Following this training, she, along with John McInnes, who later became her husband set up and ran the Deafblind Program at the W. Ross Macdonald School in Brantford, Ontario in 1971.

Together Jacquie and John co-authored the book Deaf-Blind Infants and Children – A Developmental Guide in 1982. This book was the first comprehensive reference guide for teachers, parents, professionals, and para-professionals working or living with children who are deafblind. This book continues to be the cornerstone of teacher and Intervenor training in the area of deafblindness in Canada.

Jacquie's love of deafblind children and her commitment to improving their quality of life through Intervention and the specialized programming was her ongoing legacy to all of those who were educators in Ontario and across Canada, as well as to the many children with deafblindness and their families that she has helped over her lifetime.

Jacquie connected with children in ways that were truly inspirational to all who were privileged to see her in action. She was quick to get on the floor and play with the children to be at their level. She saw abilities and gifts in these children prior to the broader understanding of deafblindness. She taught the teachers and Intervenors to see beyond the visual and hearing needs to see a functional brain that could learn. Then she taught them how to teach these children to develop their full potential.

One of the beliefs that she passed on to teachers and Intervenors was :”never criticize a parent until you walk a mile in their shoes”. As a result, parents were always respected and seen as the key to the team as they knew their child best

She gave families hope and inspiration for the future for their children.

Jacquie and John were the inspiration for the creation of the Canadian Deafblind and Rubella Association back in 1975. Jacquie was like the Mother to the young parents, whose deafblind child attended the W.Ross Macdonald Residential School.

In 1996, Jacquie received the International Association of Educators of the Deafblind (IAEDB) Award for Distinguished Service, in Vancouver, British Columbia.

A portion of her remarks upon receiving this award are repeated here:

“My association with an international group of people began as I entered the world of people who were deafblind in 1968. On my arrival at the Perkins School for the Blind I met students, fellow teacher trainees, as well as staff members who had come from many different countries and I still count many of

these as valued friends.

On my return to Canada, we who were charged with beginning the work in the field of deafblindness, turned to the only true experts we had – the families of the children who were deafblind. My gratitude goes to all of those people through out the world who have taken time to accept me into their lives and to interact with me thus enriching my life beyond words. I thank them also for lovingly reminding me of this each time I strive to be of service to them.

Thank you all, once again, for this most treasured honor. I will continue to strive for excellence and to live up to the great responsibilities which go with it. I will leave you all with this thought 'ALL PEOPLE SMILE IN THE SAME LANGUAGE'. Let us all do our best in the coming years to ensure that people who are deafblind and their families have much to smile about."

Our thoughts and prayers go to John and their family.

If you wish to contact John McInnes, personally, his mailing address is: 3297 Burnstown Road, RR#1, Renfrew, Ontario K7V 3Z4

Stan Munroe, Executive Director CDBRA

Linda Mamer, Past President, CDBRA

Norman Brown – 1936-2007

Tributes from friends around the world

We all feel the emptiness now Norman has passed away. He was a unique person, and even more unique for parents! Talking to him was like coming home. He was a very good listener, and a very kind and modest man. The first time I met him was at the European Parents Conference in Madrid back in 1995, where he presented a paper about his life with his son Steven, and talked about his frustrations, such as: "I would like to play football with Steven, ride a bicycle, do things dads normally do with their sons". "I had to find other ways to be a dad for Steven". The most impressive sentence he said at Conference, and I will always keep it in my mind, was:

"I can't bring my son to the world, so I have to bring the world to my son!"

This is exactly what we parents/families and professionals should do. If we make this our saying, I am sure Norman will be pleased.

He not only brought "the world" to his son, but to many deafblind persons and their family by his scientific works, his lectures and his parent contacts. None of us can ever give Norman back what he has given us.

Thanks Norman for all you gave to us, hope, joy, realism and family proud.
Miriam Bruggemann, The Netherlands

It is about twenty years that I had the pleasure and the honour to meet Norman again and again and to appreciate him more and more: he is – he was a really friendly, open minded and gifted man, he was so much able to look behind

things, to get the point and to communicate it in a very sensitive and elaborated way, he made us laugh and think and – he was always loyal to men, tried to catch their perspective. I always could feel his basic human confidence, and I want to thank him for that. I will miss him.

Hanne Pittroff, Germany

As a mother to a deafblind son I loved Norman Brown very much. It was always a pleasure reading his articles; listen to him in a conference or talking to him, because he was always able to give so much courage to the parents. His way of saying the right words in the right moment and in a very special way was so unique; you really understood that every word came from his heart. Thank you Norman Brown for all you gave to us parents.

Lone Poggioni, Italy

Norman was such a wonderful person and will be missed in our field but never forgotten.

Bernadette Kappen

God bless our dear friend. He had an impact on so many of us and led by example. His humor, knowledge and keen mind will be sorely missed.

Mike Collins

He was a lovely man, a tremendous teacher, he was recognized everywhere and he help in many places in the world to open doors for deafblind people.

Abrazos, Graciela Ferioli

Norman was loved and respected by everyone whose life he touched anywhere and everywhere. He will be sorely missed.

William Green

Developing housing for deaf-and-blind people in the Czech Republic.

Dana Sterbova is a University teacher in Olomouc, Petra Rosulkova is a teacher of deafblind children and Ivana Reková is President of Záblesk and the mother of a young deafblind daughter. Together they are campaigning for a life after school for deafblind children in the Czech Republic

The article deals with one of the significant activities of the civil association, Flash (Záblesk) – the Association of friends and parents of deaf-and-blind children. It is working towards setting up protected housing for deaf-blind people in the Czech Republic.

About Flash

The civil association called Flash (parents and deaf-blind children's parents)

was set up in 2001 from initiative of parents, whose children were educated in the class for deaf-blind children in the Basic School and Nursery School for deaf children in Olomouc.

The association has other aims. It seeks high-quality care for children with dual sensory loss and multiple disabilities, and promotes a secure future and life for their children. As well as this it aims to organize pedagogical-education events and programmes and activities for handicapped children and their families to encourage their social inclusion.

At present, there are 10 families with children who are deaf-and-blind from birth (congenital deafblind). The association has 35 members altogether, from a range of establishments including experts from The Special Pedagogical Centre for Deaf people in Olomouc, and those who work with the class of deafblind children.

Since we began working, deaf-blind children's parents have enjoyed many family meetings with teachers and experts, holiday stays with families and children, international sessions and seminars on deaf-blind issues generally and protected housing (Sterbová, D a kol., 2005).

The deputies of our association took part in the European conferences about deafblindness in the Netherlands, (2001), Presov (2005) and the world sessions in Canada (2003). We now cooperate with similar parents' organisations in Europe including Slovakia and share the experiences.

Protected Housing – what happens after school is finished?

Each parent starts to have a question sooner or later about future of his(her) child when growing up. Parents of deaf-blind children in the Czech Republic think of this almost daily, because it is a huge concern. The child is growing up and suddenly the day will come when they finish school and parents need to know what will happen for the future.

Partnerships with experts – at home and abroad

The help of experts is very important for the association's work. From our point of view we can call on the expertise of all those who work with deafblind children and keep in touch with them – especially education staff for deafblind classes and psychologists. Backing this up are organizations VIA, LORM and Club redwhite stick – an organization following to the adults with deafblindness in the Czech republic.

Cooperation at home and abroad for parents and experts at conferences confirm they are effective points of contact, even when the international family conferences take place in the Czech Republic. The third such as meeting was held in Olomouc in April 2006 promoted Hilton-Perkins's Programme. (see <http://www.upol.cz/zpravy/aktuality/videozurnal/zivot-s-hluchoslepotou>)

Deafblindness and possibilities of education at the present time...

In the Czech Republic, the education of children with deafblindness is supported, even if their needs are complex. The parents of deafblind children do not want to let their children remain in a closed-in environment, but they want them to have possibility to live life of their own. They want them to reach

a level of education to be able to enjoy life, like the rest of the population. At present parents try to have their child at home every day, with the family, and because of that they attend a local school. Where this is not possible some children can board – but this demands changes to family life. As parents of deaf-blind children we were worried about joining the experimental class for the deaf-blindness as we did not like to see our children only over the weekends. Ivana Reskova, mother of deaf-blind child, recalls that she and others were worried their children would live and grow up without them. But they were encouraged by the progress our children made – it was appreciable! In fact all the children achieved a lot of progress, but one of the most important aspects is self-care and communication, which is for deaf-blind people the most important.

Independent living

In the Czech Republic nowadays there is no housing suitable for persons with a deaf-blindness, which would enable them to develop their skills and personality and to be more active members of society. It is also essential to think about those people whose parents cannot care for them. They also deserve a fulfilling lifestyle.

At the moment there are only two possibilities available for young deafblind people after school. Either these children come back to their families again, or their family must put them in a social care institution, where a lot of communication barriers exist. This causes great stress to the parents as there is a lack of activity for purposeful living, and it can cause an individual damage. In these institutes of social care there are also catastrophic situations with staffing and, in the case of location of a deafblind child, or young adult, it is unimpossible to provide a satisfactory number of workers. An ideal rate is 1:1 whereas there are 14 people to every staff member at the moment. We believe that finishing the basic school is not enough as a deaf-blind person needs to be supported to continue to develop positively.

Protected Housing in other places

Complicated life conditions of citizens with deaf-and-blindness require permanent and systematic care. Today the members of our association – Flash – have already visualized another way. They have done this by visiting other countries where adult care has been developed.

The inspiration and experience from the successful foreign models of other countries in Europe is a signal for our study of protected housing – e.g. Scotland, Switzerland, England, Germany, Italy, where the high quality centres are working.

The newest trend, in Scotland, is to offer complex services into a familiar setting for the deafblind person. An organization – Tanne – in Switzerland – operates a building for deaf-blind adults at the age of 20-65 (36 inhabitants and a boarding school for the age of 4 – 20). In Italy there is a rehabilitative centre, in Osimo, that offers diagnostic, health and rehabilitative services. They, like Scotland put emphasis on a high-powered cooperation with a family. We prize our foreign friends very much: personal visits to see their services

and equipment and an opportunity to discuss new projects with their staff. Hilton/Perkins has helped us a lot. We have done a detailed study of what young people need for happiness in their future life

Our plan

We want to build assisted protected housing for deafblind people in the Czech Republic with space for 6 – 10 clients. We will be focussing on young people at the beginning. There are nowadays 13 applicants asking for this type of housing. This data comes from a questionnaire investigation (February 2006). We know this work will be effected by our ability to find the necessary funding but also by legislative issues. Mr. Jan Jakes, PhD from LORM has already made a lot of campaigning progress on deafblind issues since 1997 but getting action has been hard. The association of the Red and White can have also been supportive.

The need for establishing protected housing for this complex group of young people becomes a priority and, at a time, when children of the association – Flash – will finish their compulsory education. Working together, and with other organisations, we hope to make real progress!

(with thanks to P. Rosulkova)

The full research study and questionnaire is on the Dbl website with an extended version of this article

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14th Deafblind International World Conference

25th – 30th September 2007

Perth, Western Australia

“The conference will provide an excellent opportunity for health, education and disability professionals and support staff to meet, learn from and share ideas with other likeminded professionals and experts, with a view to enhancing the service provided to people who are deafblind and their families throughout the world.”

Debbie Karasinski, Senses Foundation CEO

Look for the conference scientific program on the website!

‘Out of isolation and into the worldwide Usher family’

A pre-conference workshop of the Usher Study Group

For professionals in health, education and disability;

people who have Usher; and families of people with Usher.

For more information and to book, see the conference website.

Book early. Places are limited and will be taken on a first come,

first served basis.

Come on – you have always wanted to see “Down Under”!
Perth is one the most stunningly beautiful cities in the world. Perth is the place to be in Spring 2007.
Come to the Conference
and see for yourself!

Register now!

www.dbiconference2007.asn.au

Voices that are heard through the silence...

Marcela Forero reports on a lively inclusive arts initiative

They have switched words for movements in a world where sound and light are completely absent. The kids and young deafblind people have made thousands of people conscious of the fact that you don't need to see and hear in order to enjoy music!

Voices of the Silence is an initiative that combines the magic of sign language with the miracle of music that we feel through vibrations. The voices of 15 girls, boys, and youth that neither see nor hear, sing with their hands, carrying the precise rhythm of the songs and interpreting what the authors have composed. With the help of young volunteers, the new artists move the hearts of the audience, transmit the warm and clear message of love, respect for differences, and admiration.

Through the sense of touch, of bare feet on the floor, signs on their backs, and the feeling of vibrations, this group of deaf and deafblind children and youth bring the message and an example that disability has no limits.

Lights, sound, smoke, and special effects, confetti... It's show time! With their firm conviction of giving a good presentation, and leaving footprints in the memory of their audience, the Voices of the Silence prepare each and every week to take center stage and sing; sing without hearing; sing without seeing, but SING!

Starting in the Autumn, their hands haven't been out of sight. With the opening concert of national artists committed to this cause, such as Ilona, Bonka, and Los de Adentro, they have demonstrated that deafblindness can actually be a powerful force for bringing together those that are interested in bringing positive change to our country.

Now have also undertaken a Christmas Show “A Song to be Felt” that brings the message that Christmas isn't just what is seen and heard, it's what is one feels in the heart. To sing with the hands, act, and inspire everyone to truly feel, is the flag that Voices of the Silence will continue waving in their campaign for the social inclusion of deafblind people!

Sense International (Latin America), has been supported by the Pescar Volunteer Network, Ideas Dia a Dia Foundation, Surcoe and Filadelfia School in achieving this wonderful production!

Marcela Forero

Deafblind International Awards

Bernadette Kappan, Dbl Vice President, invites you to participate in honouring Dbl colleagues

The months are moving along and it will soon be time for the Dbl World Confererence in Australia. The Conference brings together colleagues from all over the world for learning, sharing and celebrating. At Dbl regional and world conferences we have the privilege of honoring people who have made exceptional contributions to individuals who are deafblind and to Dbl. At this time we are soliciting nominations for awards to be given out in Australia. I hope you will take time to review the criteria for the awards and to submit names for consideration. Please submit you nominations using the process outlined. All nominations must be received by July 27, 2007.

About the Awards

Dbl has three categories of awards. At this time nominations for the Distinguished Service Award and the Lifetime Achievement Award are being announced. The Dbl Awards give us a unique opportunity to celebrate the accomplishments of our colleagues.

If you would like to nominate someone for the Distinguished Service Award or the Lifetime Achievement Award please follow the guidelines and complete the nominations form by July 30th 2007

Mail the completed form to one of the addresses below or you can e-mail the nomination. Faxes will not be accepted.

Awards Committee

Attention:

Bernadette M. Kappen

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Dbl Distinguished Service Award Nominee Eligibility Requirements

This award recognizes a Dbl member who has significantly contributed to the deafblind field or Dbl, internationally.

Examples of work in the deafblind field or within Dbl.

- Examples of contributions when thinking about a possible nominee for the Distinguished Services Award: 1) overall professional experiences; 2) innovative practices; 3) unique or extraordinary contributions to Dbl; 4) professional publications, research and/or staff training activities; 5) leadership on the international level which has promoted or improved services to deafblind individuals and their families.

DbI Lifetime Achievement Award Eligibility Requirements

The Lifetime Achievement Award will be made to an individual/individuals who has/have made a distinguished contribution to services for deafblind people on a national and international level.

- This award is recommended to be given towards the end of one's working life.
- Distinguished contributions could be in the area of: publications, research, development of new techniques or procedures, practical application of teaching techniques, training staff and parents, advocacy; and dynamic leadership.

Instructions for Nomination for the DbI Distinguished Service Award and the Lifetime Achievement Award

1. Complete the nominations form.
2. Attach a 500 to 1000-word essay, which describes the nominee's contribution to deafblind individuals.
3. Attach at least three (3) letters, which support the nomination. These letters can be from colleagues, parents, deafblind individuals, employers or others who can comment on the nominee. The letters should present information that conveys an accurate picture of the nominee's achievements and contribution to the field of deafblindness.

DbI Distinguished Service and Lifetime Achievement Awards Nomination Form

Please type the following information so that it can be easily read or scanned. Forms or letters not presented in this manner will be returned.

I would like to nominate: (Please complete a separate nomination form for each award/nominee)

Name of nominee:

Address:

Telephone Number:

E-mail:

Is this individual a current or past member of DbI? Yes No

For the following award: (Please check one)

Distinguished Service Award Lifetime Achievement Award

Name of nominator:

Address:

Telephone Number:

E-mail:

Please remember to attach:

1 The statement which describes the nominee's contribution.

At least three letters of support. (see page 54)

International meeting on deafblindness in the elderly

Ole E. Mortensen, Director, Information Center for Acquired Deafblindness, Denmark reports on this meeting of professionals from all over Europe

Concepts in ageing

“Double ageing” refers to the situation when an elderly person develops a health or mental problem in addition to the problems directly linked to age. As the term implies this puts the elderly person in a more difficult situation than their normally ageing peers and creates the need for special support services very prominent.

The term “double ageing” was one of many interesting terms, ideas and facts that were presented at an international meeting in Osimo, Italy in December 2006. The term was put forward by Trees van Nunen and Jan Trommelen from the Netherlands to a group of 23 colleagues from seven countries who were invited by the Lega del Filo D'Oro to take part in a discussion about deafblindness in the ageing population.

The main purpose of the meeting was to get an overview of the way different European countries have arranged their services for elderly with deafblindness, both congenital and acquired. To have as productive a meeting as possible, the meeting's organiser William Green had asked everyone to prepare their presentations based on the format of the international survey of deafblind services that Rodney Clark conducted in the late 1990s on behalf of the Lega del Filo d'Oro. This provided a homogeneity of and framework for the information given that should facilitate immediate understanding and discussion.

William described the topic of the meeting as the building in which the actual services exist. So in order later to look at, and discuss different types of service for elderly people with deafblindness, it is important to first look at the preconditions that exist for these services based on the political, geographical, cultural and financial situation in the individual countries.

To spark of the discussion, Tony Best, executive director of Sense, described a number of factors that in his opinion will influence our work in the field of deafblindness in the next few years. Among these are older people with acquired vision and hearing loss: "Awareness is increasing of vast numbers of older people who develop sensory impairments, but this will need a profound change in our culture, skills and resources if we are to meet their needs." And at the same time, there is an increasing awareness of people with congenital deafblindness who are now approaching old age which also calls for special considerations.

At this meeting the discussion was nurtured around the heterogeneity of the group. Participants came from different countries, with different professions – medicine, social work, administration, rehabilitation, information, psychology – and from both parts of the field of deafblindness, congenital as well as acquired. The result was very fruitful and diverse discussions with many different perspectives coming into play.

The Lega Del Filo D'Oro is now working on preparing the proceedings from the meeting in Italian as well as English to make sure that the outcome of the two days will be available for as many colleagues as possible.

Co-Creating Communication with Persons with Congenital Deafblindness

Theory and Practice

Wednesday 8th – Saturday 11th October 2008

The Royal Armouries Museum, Leeds

The Programme

The Scientific programme for the conference will be organised with the DbI Communication Network. This group has organised European conferences to share their latest research and work in co-creating communication with congenitally deafblind people. This exciting event brings together researchers and practitioners, discussing the co-creation of communication and exploring both theoretical and practical interventions.

The Participants

The conference is aimed at professionals, families and researchers involved in co-creating communication with people with congenital deafblindness. The conference is open to participants from all countries and the working language is English.

Conference Fee

£335.00 per person – (includes lunch, tea and coffee, gala dinner and conference papers) Accommodation is available at reasonable additional cost in the locality of the venue.

Leeds is the commercial and cultural capital of the North of England where international visitors will find a great atmosphere! Join us!

To register or to request further information contact:
conference2008@sense.org.uk

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Samantha Scholefield
Paul Hart

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Paul Hart, UK
Mary Foster, UK

Secretariat and Management Committee News

Management Committee News

This has been a busy period for the Dbl Management Committee. Since its previous meeting at Boston in November 2006 and the recent one held on 27 – 28 April 2007 at Lega Del Filo D'oro in Osimo, Italy, the members have been closely following up on the developments made by both the Dbl Strategy Review Group and the Nominations Committee. The new Strategic Plan will be presented to the General Assembly during the Australia Conference. The elections for Dbl office bearers will also take place at the General Assembly. The next meeting of Dbl Management Committee and Council will be held respectively on 24 September and 25 September, at Perth, coinciding with the Dbl World Conference. The General Assembly is scheduled on 26 September. The new Council and Management Committee members will have their meetings on 27 September. For more news and details on the meetings contact the Secretariat.

Dbl World Conference

Only four months to go! If you still haven't registered, please do so at <http://www.dbiconference2007.asn.au>. Up to date details about the available

accommodations and travel, pre conference workshops, family activities and tourist day information is also available in the website for your use.

The Scientific Committee members met in February 2007, at Perth to screen the abstracts received and develop the full scientific programme. You can view the Scientific Programme on the conference website in June.

The local Planning Committee and Dbl Council members are keen to encourage participation from the developing countries. Applications for sponsorship have been submitted and we will be hearing about final acceptance, shortly.

Please note the dates once again – 14th Dbl World Conference, 25-30 September 2007 at Burswood Resort in Perth, Western Australia. For more information please visit

<http://www.deafblindinternational.org/standard/conferences.html> or contact Conference Planning Committee at conference@senses.asn.au

Membership Update

This has been a busy period with much time spent on chasing up lapsed memberships and facilitating payments. The Dbl members are encouraged to renew your membership. Your name has been removed from the back page of this magazine, if you have not paid your fees. And you would not have received your own copy of this magazine.

Individual members are also requested to pay your membership fees at the earliest. Please note that you can now only pay for a four year period.

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

http://www.deafblindinternational.org/standard/c_membership.asp to make your payment. Also remember to quote your specially assigned membership number in all communications. Let us know if you have any problems.

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!

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

If you have any queries regarding the status of your membership, please do not hesitate to contact the Secretariat.

If you have any queries, please contact Sumitra Mishra or Parag Namdeo at: secretariat@deafblindinternational.org

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

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

network. Non-voting members will receive a copy of Dbl Review and other relevant Dbl information.

Non-voting membership costs 30 a year or a discounted 100 for four years. Voting Members are the representatives of corporate members who have paid their subscription fees, and the representatives of recognised Dbl networks.

There are now two tiers of Corporate Membership:

Large Corporates:

Annual Fees between 3,000 and 5,000

Small Corporates:

Annual Fees between 300 and 1,500

Corporate Members can be nominated to sit on the Council.

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