

DbI Review

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

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

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

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

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

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Cover: Holy Land Institute of the Deaf and Deafblind Jordan

A message from the president

Dear Friends and Colleagues

I

would like to take this opportunity to wish you all seasonal greetings and a prosperous 2009.

2008 has been an extremely active year for DBI. Many activities and developments have taken place, with the contribution of our membership, and the dedication of our council and management committee. Only a few weeks ago, Gill Morbey brought together the leaders of the groups, which are focusing on the implementation of the strategic plan. Sixteen people have agreed to actively participate in the different teams. This is proof of the willingness of members to contribute to future progress. The information function is also being discussed. A group of information specialists from our membership have also come together to discuss the strategic proposals and to develop a way forward to meet its aspirations. A full report of their work will be presented during the European Conference to be held in Senigallia in September 2009. I hope to see many of you there.

Three events, which were extremely successful, have taken place in Scotland, Norway and England. The first of these brought together families from several different countries to share experiences and have fun! In Leeds, the Communication network inspired a huge professional audience with an in-depth training style conference. The third event, organized by the Acquired Deafblindness Network, once again created the scene for professionals to share and exchange philosophy and actions for this important population. Heartfelt congratulations and thanks to all those involved in the organization of these special events.

In addition to the daily work, I have had the opportunity to see a theatre performance of deafblind people in Tel Aviv, which was unforgettable. It was the anniversary of this theatre group, and congratulations are in order for the amount of work that has been invested. The acting ability of these deafblind professional people touched the hearts of all the audience, as I am sure the 60,000 people who have seen this show world wide during the year agree.

I would at this point like to welcome Richard Brook, the new CEO at Sense UK, and Sergei Sorokin in his new role as Director of Hilton Perkins, USA. Sense and Perkins have contributed enormous amounts of expertise, resources and support for Dbl, and I look forward to an ongoing close relationship.

The Council has an extremely important role in the running of our organization. It is encouraging to note that more of our members are keen to join Council as they wish to take an active role in Dbl affairs. Stan Monroe has recently joined the Management Committee and we are sure his knowledge and skills will contribute greatly to our organization

Once again, and without fail, I would like to thank each and every one of you for your invaluable support.

William

Editorial

Dear friends

This edition of Dbl Review paints a splendid picture of the mixture of individuals and organisations that form our membership. We read about endeavour and determination which, coupled with skills and knowledge, brings about amazing changes for individuals who are deafblind. Good services are being developed all over the world – sometimes against the odds – like those in Burundi and Jordan. We hear some of the great successes and lighter moments from Lynn in Canada, who, with the right communication support has changed her life for ever and Murray, whose visit to Lapland with deafblind friends makes a very amusing diary! And all your news is here too.

Apart from the magazine I have been working towards the implementation of the strategic plan for the Dbl Information function. I am fortunate to have some information specialists from our member organisations helping me to think it through! The intention is to provide much more material electronically and create the space for members to get together more effectively, using our website and other creative technologies. We are working hard to be practical and resourceful but one thing is certain – our news sharing will be changing its format in the future!

Compliments of the season! And keep your news and stories coming in!

Eileen

Contents

CONTENTS

A message from the President	page 2
Editorial and Contents	page 3
Articles	
Home Sweet Home	
Susan Managhan	page 4
Co creating communication in Switzerland	
Henriette Erlich	page 9
Burundi – a young country with plenty of challenges!	
Jacques Souriau	page 13
Deafblind people and self identity	
Ina Mance	page 17
And miles to go...India training programme	
Anuradha Bagchi	page 20
The sensory integration perspective	
David Brown	page 22
The deafblind capital of Jordan is Salt!	
Jacques Souriau	page 33
Making friends, music and meeting reindeer in Lapland	
Murray Farquharson	page 36
Evaluating the use of equipment in multi-sensory environments	
Gary Hyndman	page 39
Information technology for deafblind people	
Ximena Serpa	page 50
UN Update	
Lex Grandia	page 57
Network news	pages 27 – 32
Country News	
Denmark Ole Mortensen	page 7
Colombia Ricardo Zevallos	page 18
Romania Teodora Sieciuc	page 38
Australia	page 43
England	page 45
Scandinavia	page 46
Italy	page 47
USA	page 48
Conferences	
DbI European Conference Italy	page 8
ADbN Conference report from Bergen	page 28
Leeds Conference report	page 31
WFDB World Conference Uganda	page 42
ADEFrav – Symposium on social inclusion	page 51

Listen 2 Me 5	page 59
Our Partner's reports	
WFDB – work in Africa	page 54
ICEVI – developments in Latin America	page 56
Secretariat and Membership News	
DbI Awards	page 60
News from the Secretariat	page 62
Membership Form	page 63

Home Sweet Home – a deafblind woman's journey

On March 28, 2008, as part of the provincial government's initiative to close their long term care facilities in an effort to place the residents in community living type settings, Lynn Todd's life changed significantly. That was the day Lynn departed Southwest Regional Facility, and came to live at a DeafBlind Ontario Services home in Kitchener. It was the day Lynn's life was forever changed.

Lynn lived in a facility for the developmentally challenged for 44 years. Lynn is also deafblind.

Some of the Intervenor's at Lynn's new house had visited her at Southwest Regional Facility several times during the month of February as part of the transition process. Initially, we shadowed the Facility staff while they supported Lynn during her daily routine, and then, as the visits progressed, we actively participated in her routines. These visits provided us the opportunity to get to know Lynn and to begin to develop relationships with her, which we could build upon in her new home.

Throughout her life, Lynn's dual sensory loss had limited her ability to communicate, and probably inhibited those providing her with support in the facility from developing an effective communication system with her. As a result of this, Lynn had developed alternative coping strategies to convey her needs. These coping strategies usually took the form of self-injurious behaviours, which became Lynn's primary method of communicating. This was how Lynn dealt with her frustrations and emotions, her inability to interpret her environment, and convey her need for sensory input and stimulation. While Lynn was physically cared for in the facility, she was not exposed to intervention, something we felt strongly would benefit Lynn.

We were told during our initial visits with Lynn at Southwest Regional Facility that she was non-ambulatory. Due to Lynn's self-injurious behaviours, she spent 18-20 hours a day in bed or in her wheelchair, often in restraints. Not unexpectedly,

when Lynn arrived and joined us at her new home she continued to use self-injurious behaviours to communicate her needs.

We felt confident that after Lynn arrived at her new home we would eventually be successful at developing alternative communication strategies with her, but it was going to take time and a great deal of patience. This confidence came from the knowledge that at Deafblind Ontario Services, we provide one-to-one intervention and specialize in supporting people who have a dual sensory loss. Our staff, who are known as Intervenors, undergo intensive training to develop the skills to enable them to communicate with our residents and enable the residents to develop their own communication system. This specialized training was developed by Deafblind Ontario Services and is known as the Total Communication Curriculum (TCC). Our Intervenors work one-on-one with our residents each day to provide them with the communication required to enable them to interact with their environment. Through the communication and information provided by our Intervenors, our residents are able to engage with their environment and fully participate in recreational, social and vocational activities.

Day One

Lynn arrived at her new home in the afternoon of March 28, 2008. Arriving at the same time was one of her new house-mates, Sean, who was also a resident at South West Region. Sean, like Lynn, is also deafblind.

When Lynn and Sean arrived, they both seemed agitated from their journey. The Intervenors who greeted them hoped they would remember us, and it appeared they did. The one-on-one intervention had begun.

The time of arrival was planned around lunchtime, and we had a meal ready for them, which provided a calming and enjoyable focus.

After lunch, the Intervenors began the process of orienting them with their new surroundings, guiding them from room to room, providing them with sensory input hand-over hand. They were both receptive to this input at times, and at times quite curious about the new sensory input. At other times, they were unreceptive and reverted to their traditional coping skills. Because they were unfamiliar with their new surroundings they both found it difficult to relax and settle, they seemed to be searching for their familiar surroundings. Throughout that first day, Lynn and Sean's Intervenors continued with the process of orientation via sensory input. While Sean appeared to settle and relax a little as the day wore on, Lynn found it much more difficult and wanted to be constantly on the move, and her self-abusive coping skills were frequent. We patiently continued with the one-on-one intervention, redirecting her to avoid injury and providing as much sensory input to her as we could.

Day 2

The following day brought more of the same for Lynn; she found it difficult to settle and preferred to be constantly moving. Her self-abusive coping skills continued at, what seemed to us a high rate, but we pressed on with the one-on-one intervention,. This process continued for the first couple of weeks after Lynn's arrival. Lynn was constantly restless, displaying frequent self-injurious behaviours. It was a very challenging time for both Lynn and her Intervenors.

Introducing Choice

As Lynn became familiar with the layout of her new home, the Intervenors showed her how she could trail along the walls from room to room, giving her choices in where she wanted to go. Lynn has selected two favourite places for relaxation: her bed and the living room sofa. When she wants to relax, or have some down-time, she will now take the initiative and lead her Intervenor to one or the other location.

Although Lynn was considered to be non-ambulatory, we had provided Lynn with the option of leaving her wheelchair while in her home and gradually, Lynn came to regard this as the norm for her, ultimately rejecting her wheelchair when it was offered to her. Lynn preferred to walk, assisted by an Intervenor, at every opportunity.

After a few weeks, Lynn began to be much more receptive to the hand-over-hand sensory information provided by her Intervenors, indicating she was recognizing this input as providing her with useful information. Lynn is now very receptive to hand-over-hand intervention. Realizing that she has an alternative way to communicate her needs, Lynn will now reach out for her Intervenors to receive information and communicate with them. She has begun to establish a bond with her Intervenors.

Lynn's family

Lynn's parents were apprehensive at first about Lynn coming to DeafBlind Ontario Services. They had no idea that agencies like ours existed, that we supported other people like their daughter.

Shortly after Lynn moved into her new home, her parents came to visit. For the first time, she sat at the kitchen table with them over coffee and a muffin. That day, she walked over to her father and gave him a big hug and didn't let go. Her father was quite emotional at that moment, as it had been years since Lynn had hugged him.

As Team Leader Shari Chantler said, "it was awesome".

Lynn Today

Through the support network established through the facilities initiative, Lynn has been provided with access to the following resources: Health Consultant, Nutritionist/Dietician, Behavioural Consultant, Occupational Therapist, Physical

Therapist, and a Sensory Consultant. These supports have been invaluable in ensuring Lynn's quality of life in her new home.

Lynn is now actively exploring her community. She takes part in a swimming program, massage therapy, music therapy, and a little art therapy, all of which she enjoys. Lynn has spent the summer at local parks for picnics, cultural festivals, farmers markets and walks. She visited a local horse stable where she was able to groom and pet the horses. She even went on a day outing to a local amusement park!

With the assistance of her Intervenors, Lynn is learning to: bake, prepare meals, pour her own drinks, clean her room and grocery shop.

Lynn is very relaxed in her new home. While Lynn still exhibits some self-abusive coping strategies, we have seen a dramatic decrease in these behaviours. The daily rate has now dropped to 8% of what they were when she first arrived. Most days, it's zero. From the very beginning, we have not used restraints with Lynn, and with one-on-one intervention, she has shown that it is unnecessary.

We attribute these successes to the continued development of an effective communication system that is unique to Lynn and her abilities. Lynn has made many strides in the 7 short months we have been fortunate to know her. We will continue to develop a total communication system for her, which when fully developed, will involve the combined use of cues, sign language, and calendar systems. Effective intervention will enable Lynn to take control of her life and reach her full potential.

At DeafBlind Ontario Services, we believe that – with a helping hand and supportive touch – deafblind individuals can increase their independence – on their terms. At 51 years of age, Lynn's life is in many ways just beginning. We are excited to be a part of Lynn's journey, and are in constant amazement watching her progress and grow.

DeafBlind Ontario Services provides specialized housing and 24/7 support services to congenitally deafblind adults across the province of Ontario.

Visit us at www.deafblindontario.com.

Would you read our magazine if it was published in English?

...asks Ole E. Mortensen, Director, Information Center for Acquired Deafblindness, Denmark

This was one of the questions we asked you, the members of the Dbl, in April 2008.

Our Danish quarterly magazine “NYT” (“News”) is aimed at professionals and contains news and information on a variety of aspects of acquired deafblindness. An English version of the magazine could be a kind of contribution to the international network of professionals and to the international exchange of information and experiences within the field of acquired deafblindness. That was our thought. The aim of the questionnaire, which we sent out to you, was to get an idea of the interest and possibilities for financial support among the members of the Dbl in order to make a decision on whether or not we should start publishing an English language version of our magazine as well.

We had one of the recent issues of the magazine translated and designed in a PDF format. This trial issue was sent by e-mail – with the invaluable assistance from Dbl’s Eileen Boothroyd – to all the members that Dbl has e-mail addresses for. In the e-mail was also a link to an online questionnaire.

We want to thank those of you who participated for taking the time to reply, and for the interest you expressed. However, our conclusion is that the number of replies we received is too few to give us the right basis to make the investment (both money-wise and time wise) that this project would require at the moment. Furthermore, with the introduction of Google Translate another possibility has recently presented itself. This web based tool provides automatic translation between 23 languages (so far) – including Danish – so by using this tool you can get a rough translation of the articles in our magazine when it is published online (March, June, September, December) at www.dbcent.dk/NYT.

And if you are interested in knowing more about any of the articles, you are very welcome to contact us.

You can find Google Translate at www.translate.google.com.



lega del filo d'oro

DEAFBLIND INTERNATIONAL
7TH EUROPEAN CONFERENCE 2009

**TIDES
WAVES AND
CURRENTS
IN RESEARCH
AND ACTION**

22nd to 27th September 2009
Senigallia, Italy

www.dbiconference2009.it

Co-Creating Communication in Switzerland

The connection of theory and practice – an example from Tanne, a Swiss foundation for deafblind people, in Langnau/Zürich
Henriette Ehrlich

“I recognised that I do a lot of things intuitively and correctly. My long professional experience certainly plays a role in that. But it is so good to connect my daily practice with the theory again, to reflect and sensitize myself anew! The examination of the Co-Creating Communication model and video analyses has provided me with huge motivation to develop my work“.

This statement is from a support worker of Tanne. She wrote it in the evaluation form after this years project days in September 2008, where the whole Tanne staff had 3 days for an examination of the co-creating communication model, especially with the relevance of social interaction.

Tanne means “fir“and is a Swiss foundation for deafblind people. It is the only centre for deafblind and dual-sensory-impaired, multiply disabled children and adults in the German speaking part of Switzerland and is based in Langnau – a small town near Zürich. The services include, amongst others, early education, school, educational advancement, living support and engagement for adults, various therapies, consultancy and further education for professionals. Tanne has been involved with this specific target group for 40 years and takes care of 55 people today (www.tanne.ch).

The special needs of sensory impaired people at Tanne make a continuous, intense discourse with deafblind education theory and the exchange and cooperation with international partners necessary. Barbara Bettenmann took that role for many years but when she stood down in 2006 Tanne invested in that important part of the institution and sent a support worker as one of the first students to the new Masters programme “Communication and Congenital Deafblindness” which is organised by Dbl`s European Communication Network and the University of Groningen in The Netherlands. And that person is me: Jette Ehrlich.

Because the lecturers of the programme are leading heads in the development of deafblind education approaches, I could learn within one year a lot of specific and specialised knowledge, which is of high relevance for Tanne. After that I had to implement my new theoretical knowledge in practice and most importantly transfer it to my colleagues!

For that purpose we planned 3 project days and invited two international colleagues to share with us. Ms. Andrea Scheele, a PhD student at the University

of Heidelberg, Germany (projects: “Dual-sensory-impaired children in dialogue with their parents” and “Dialogical development in infants“; www.andrea-scheele.de) and Mrs. Marga Martens, a consultant in deafblind education from Viataal, The Netherlands (www.viataal.nl). Both are alumnus of the Masters programme “Communication and Congenital Deafblindness” and PhD students at the University of Groningen. Our topic was: Co -Creating Communication – Communication development through social interaction.

Day 1: Presentation and refreshment of the theory

Although the CCC Model is already known in Tanne and builds the basis for our pedagogical work we refreshed the knowledge of the seasoned professionals and explained it to the newer staff (see picture 1).

The CCC Model is based on the assumption that the communication development of deafblind people is the same as that of non-handicapped persons, but under different circumstances: without seeing and hearing or with an impairment of these main distance senses.

Within social interaction between two partners (which means being together, experiencing something together, playing together and sharing emotions), who co-regulate proximity and distance and who are in interaction with their environment (exploration), important presuppositions for communication are developing. Those are e.g. reciprocity, dialogicality, joint attention, intersubjectivity, etc. For that reason it is very important for us within education of deafblind people to know certain features of dialogical social interaction and to realize them.

Those features were presented using the model of the process of interaction that Bernadette van den Tillaart (2001) developed and illustrated by video examples out of the Viataal booklets “Communication and congenital deafblindness“ produced by members of the Dbl ECN.

Day 2: Social interaction in daily practice

On the second day the staff were asked to observe themselves and each other within their daily practice and to relate their acting to the process of interaction. In addition they should try to consciously observe the impulses and actions of the deafblind persons which they could react to, in order to co-create a spontaneous game. They were accompanied by camera-people who taped some interaction scenes on video and by us – the lecturers – who observed, supported and advised them.

Day 3: Video analysis

On the third day we met in smaller groups in order to analyse selected video sequences regarding the process of interaction and social-cognitive abilities. We discussed questions like: Do we see symmetric dialogues? Are the partners

reciprocally turn-taking? How do they co-regulate proximity and distance? Do they share emotions? Can we see joint attention?

One month later the whole Tanne-staff met again and had a second look on the process of interaction. But this time we illustrated it with their own video sequences. Indeed the support workers, teachers and therapists were often acting consciously or unconsciously in the way the theory of Co-Creating Communication advises us. They produced excellent video examples which explained the theoretical input much clearer to the people. Now they felt more confident about the meanings of all the theoretical concepts and were impressed by their own work. That motivated them and made clear how important it is to concentrate on emotionally bonded, social interaction within communication development.

In order to implement the theoretical knowledge in our practice for the long term we start in 2009 with a new feature within the process of diagnostic intervention. The key worker for each resident or pupil has to do at least one video analysis within a team meeting. They will analyse sequences of social interaction for the purpose of assessing the present state of the individual's communication development and of planning further steps in communication intervention. For that we will use different guidelines and tools which are based on the Developmental Profile (Nafstad & Rødbroe, 1999) and with that try to get more information about how the profile could be used for assessment – in order to recreate and adapt it .

To continue the process of connecting theory and practice, we will do a follow-up. We will organize 3 project days again in 2009. The focus will then be on the upper part of the CCC Model: Gestures, Meaning Making and Tanne-Sign-Language (www.tanne.ch/gebaerden).

Organisational learning is a must

Though it gives us important cognitions and tools it is not always easy to integrate the theory, which sounded so logical and reasonable when heard at one of Dbl's conferences, into daily reality. In order to reach deafblind and dual-sensory impaired persons who should benefit from this approach, the theory must get to the front line workers: to those people who live and work in different situations, everyday, with the deafblind person. Support workers, teachers, therapists or nurses have to get support in what they are doing. They are the interaction partners of deafblind people. It is important that they have confidence in themselves and feel good while doing a job, which can be very challenging. From our experience specific knowledge is often developed intuitively and pragmatically and stays in the heads of those people. It is then dependant on individual professionals. If we do not have generally available basic principles and guidelines, our aims are jeopardized.

As a specialist institution within a small, special pedagogical field, Tanne is extra challenged to build up premises for organisational learning. We want to collect, exchange, deepen, document, develop and use the experiences and new findings which come from the practical field. We need more than pure gathering of theoretical knowledge. The much more important and difficult task is to translate expert knowledge to the practice. It is effective to learn directly at work where you have to cope with current challenges and where professionals can support and advise them to each other in both a human and professional way. This works thanks to organisational and administrative support for the staff by the management and a generous allocation of pedagogical and technical methods and tools.

With this years project days we did a further step to the connection of theory and practice but we must not stop working on it continuously!

Tanne is

The intercantonal centre for deafblind or dual-sensory impaired persons in the German-speaking part of Switzerland. Services are: consultants, care and education for deafblind, dual-sensory impaired and other sensory impaired people.

In detail:

Special early education and consultants

Special school (19 places) and residential school (15 of 19 places)

Residential home and occupation for adults (36 places)

Training in daily life skills

Music and Dance

Special training for vision and hearing

Orientation and mobility

Therapeutic horse-riding

Physical therapy

Occupational therapy

Consultants, education and staff training

See:

- www.tanne.ch

- Tanne-sign-language: www.tanne.ch/gebaerden

- Schneider & Schuler, 2002, Kommunikation mit taubblinden Menschen

Ehrlich, 2007, The Developmental Profile as a baseline assessment of an adult who is deafblind

Burundi – a young country with plenty of challenges!

Jacques Souriau writes...

One of the good aspects of being “pensioned” is that you (think that you) have time to do things that you were too busy to do before. One of these things was to work with colleagues that had started a program for deafblind children in Burundi. Gervais Kiyakara, a colleague of mine in the school for Deafblind children I was the head of in Poitiers, informed us about the existence of this very new program. Gervais was born in Burundi, not far from the city where the program is being developed and happened to meet the leader of the school for the deaf where the deafblind children receive their education. Therefore, in February 2007, I organised my first trip to Burundi along with Gervais and my wife Mamie, who is also a professional in the field of deafblindness.

Burundi is a small country (27,834 Km, around 8 million people – half of it below 15 years of age) surrounded by Tanzania, Rwanda and the Democratic Republic of Congo, near the Lake Tanganyika. It is not far from Uganda and Kenya. The density of the population is very high and it is one of the poorest countries in the world. The capital is Bujumbura (on the Tanganyika Lake) and the second biggest city is Gitega, where the program for the deafblind is developed.

In the past, Gitega was the capital of the country. Recently, some of the state administrations moved from Bujumbura to Gitega, giving back to this city part of its previous status. It is in the middle of the country, in the mountain, and the climate is much cooler than in lower parts. One of the most important organisations in this city is the Archbishop’s headquarters. In Burundi, the Roman Catholic Church plays a central role in education and social services. The Gitega school for the deaf, known as CESDA/NDP Centre d’Education Spécialisée pour Déficients Auditifs – Notre Dame de la Persévérance (Specialised Education Center for Hearing Impaired – Our lady of Perseverance) is one of the programs that the Archbishop runs, along with a school for the Blind, a school for people with a physical disability and a school for children with learning disability.

When we arrived at this school, in February 2007, 250 deaf children and youngsters welcome us with an amazing traditional drumming and dancing performance. We immediately felt the warmth and creativity emanating from this little community, in spite of its very limited financial resources.

The staff and children

Spes Bandora, the leader of the school introduced us to their first deafblind student, Aline. The three of us gave her the time to make contact with us and our first surprise is that she lengthily explored the back part of our heads with her

hands (while keeping Spes' hand in her left one). It did not take long until she trusted us as reliable partners. It was possible then to engage with her in explorative games that she immediately loved. We also discovered that, although all the children and staff of the school used sign language, they had not yet realised that it was possible to use it in a tactile way with deafblind children. Aline appeared to us as a very social person, very expert at exploring in a tactile way and with a very good orientation. She had not received yet a specific deafblind education, but her many contacts with the deaf students probably gave her a very good context to develop her social skills. We noticed that the older girls in the school spent time with her to help her with self help skills and also just to be with her in after school activities.

A few days later, we met Ghyslaine, who is not a typical deafblind. Her sensory impairment is not easy to assess since it is associated with motor disabilities. She came to the school with her mother who had to deal with a lot of problems at home (her first priority being to feed the family). For her, finding a place for her daughter in a school was a blessing since it guaranteed attention, food and education.

Spes Bandora, the leader of the school for the deaf, offered to introduce us to the deaf students with visual impairments. All of them were able to attend the program for the deaf but with difficulties related to reading on the blackboard (the most important educational device in this context) or to orientation in the buildings during the nights (especially when electricity breaks down); more important, they were deprived of communication when in the dark, since they could not perceive the signs visually. We organised with them and their friends a crash course on how you can guide and be guided in the dark, and also on tactile sign language.

After a few days, we had a better view of the situation. The potentials are quite remarkable, mainly regarding the social context. The deaf community has the relevant communicative skills and the deafblind children are not separated from them. They benefit from a fantastic tactile environment that would be difficult to provide in European countries. These children also get from the leader of the program, Spes Bandora, the conditions for a very secure attachment. She is good at being in contact with them personally and at finding the right partners for them.

Although our trip was quite short, we managed to make contacts with local and national authorities, which helped the school to get more attention from them. We also helped the leader to organise a program which would give more staff to the deafblind children and facilitate the enrolment of new ones. And these children became our friends.

Our return

We came back in February 2008 and met two new students. Our plan was to spend two weeks in an intensive staff training program. Unfortunately, an

unexpected family event obliged us to fly back home after two days. However, we had time enough to see that the program was on the right track and we even managed to work enough with the staff and students to make a difference to it. We will go back to Burundi in February 2009, hopefully for a much longer time. We also understood from our exchanges with our friend Spes, the leader of the program, that the increase in the cost of cereals provoked a shortage of food, the consequence of which being that the children get only one meal a day in this moment. We worked at raising money for them but much is still to be done. Our colleagues there are fantastic and we will go on working them as regards staff development. We must not be misled by the huge economic problem, in our judgment, concerning their program. They need financial help, yes, but they are reliable colleagues. The quality of their work is already much higher than in many settings we can still find in “developed” countries.

Would you like to help?

As the reader has understood, any financial help is welcome. We have set up a system for collecting money for individual scholarships for deafblind Burundian students. Money can be sent to ANPSA – 18 rue Etex – 75018 PARIS, with the mention “deafblind students Burundi”. You can also contact me through my email : Jacques.souriau@wanadoo.fr .

Jacques Souriau

Deafblind People and Self-identity

new findings based on interviews in Denmark and New York

By Ina A. Mance, Information Center for Acquired Deafblindness, Denmark

How do people with acquired deafblindness describe or think of themselves? What does it mean to call oneself deafblind and not, for instance, Deaf with a vision problem or hard of hearing with retinitis pigmentosa. The list of diagnoses is long – and so is the list of terms that can be used by people to describe themselves. So, who chooses to use the term “deafblind” to self-identify and describe themselves?

The Information Center for Acquired Deafblindness, Denmark and Ilene Miner from New York City, USA, set out to find answers to these questions. Ilene Miner is a Clinical Social Worker and was until recently the Director of Mental Health

Services at the League for the Hard of Hearing in New York. Today, the answers are at hand, and the paper “Deafblind people and self-identity” is now available.

Views on disability and services available make the difference

We wondered if the process of self-identification as a deafblind person is similar or different in communities that have differing views of disability issues and differing kinds of services and access. Rather than focusing on a person’s functional impairment, the focus in Denmark may be on how the situation can be compensated in a manner that, ideally, can equalize the person with others. In practice, this philosophy results in laws that result in a variety of services being provided, many of which are virtually unknown in the US, as Ilene Miner states in the paper.

We decided to make a comparative study and to interview deafblind people in Denmark and in New York, US, letting the two places represent communities that have widely differing approaches to the provision of routine services to people with disabilities.

In all 27 deafblind people were interviewed – 14 in Denmark and 13 in the US: 16 women and 11 men. In the Danish cohort there were 7 sign language users, 3 of whom use tactile sign language. In the American cohort there were also 7 sign language users, 5 of whom use tactile sign language. All interviews were conducted by Ilene Miner, and in sessions of 1-1.5 hours the interviewees were asked about their lives and living circumstances, their experiences, and their issues about identity and self-identification.

Yes, I am deafblind!

The interviews show that 11 of the 14 Danish interviewees self-identify as deafblind. They experience that being deafblind is their identity. This is the case for both sign language and spoken language users. A few call themselves culturally Deaf, either simultaneously with their deafblind identity or secondary to it. However, in the cohort from New York with 13 American deafblind interviewees, only two experience having a deafblind identity.

There is no doubt that experiencing and developing a self-identity as deafblind is very closely connected to:

- the rights given by law
- the services available
- the possibility of access to a community where there are other deafblind people

All of the Danish interviewees who self-identify as deafblind are active in FDDB (The Danish Association of the DeafBlind), they participate in FDDB events and activities, where they meet other deafblind people. Similarly, the two people in the US cohort who self-identify as deafblind both have access to a context of other deafblind people.

The paper “Deafblind people and self-identity” contains many examples and stories from the lives, experiences, and psychological processes of the deafblind interviewees. For instance, they talk about their reactions upon diagnoses and the psychological implications of becoming deafblind “all of a sudden”. It also explores what it takes to find a new identity or to reconstruct an old one.

Contact

You can download the report “Deafblind people and self-identity” from the English section of our website at www.dbcent.dk.

Here you may also download or order a copy of another of our publications, “The Nordic Project – experiences from deafblind people”, in which 20 deafblind people in Denmark, Sweden, Norway and Iceland were interviewed once a year over a five year period.

Deafblind people take action for their rights!

Ricardo Zevallos reports from Peru

Because the rights of deafblind people seemed to be so far away in Peru, Sense International (Latin America) took the initiative of creating a law project to recognize deafblindness as unique disability. Included in this work was the recognition of the communications systems and the certification and registration of guide interpreters as a priority in order to guarantee access to information and communication for this social group.

This Law Project presented on June 27th 2008 has seven (7) articles and five (5) complementary dispositions; it was promoted by the institutions that are part of the network that works for deafblindness, created in Peru in last April. A workshop for 20 young adults was organized to express their opinions and validated the initiative.

This initiative looks forward to government decisions related to the integration of deafblind people in Peru, such as the Education ministry offering to train guide interpreters and obligates the public and private institutions to offer guide interpreters as a free service to deafblind people who are registered with the ministry.

In a public event, the Law Project was given to the congress President of the Commission of the Disabled, Mr. Michael Urtecho, as well as a drawing, done by a deafblind young adult. Also two deafblind people talked about the international day of deafblindness and congratulated the government on their commitment to them.

This important event, that begins to reflect the vulnerable situation of this population, is the result of the planned work. It was stimulated by the Andean parliament's decision 1217, published on the official news on June 2008, to exhort to the members of the Andean Nations (Bolivia, Colombia, Ecuador, Peru and Venezuela) to adopt legislation, executive and administrative steps to recognise deafblindness as a unique disability and to introduce the implementation of specialized services education, health, work and human development to satisfy the needs of the population on education, health, work and human development.

And miles to go...

Anuradha Bagchi, Course Co-ordinator from the Teacher Training Center at the Helen Keller Institute for Deaf & Deafblind People, Mumbai, India, reports on the way the training course is transforming the educational opportunities for deafblind children and young people across India and SE Asia by producing a committed group of new specialists!

A trip down the memory lane takes us way back to the years when the world of deafblindness in India was truly dark and silent. There was no awareness that such disability truly exist. Although Helen Keller Institute for Deaf and Deafblind children started providing services to children with deafblindness from 1977 the professionals trained to train and educate this population with dual sensory impairment were only a handful.

By the year 1997 Sense International (India) had already identified 450,000 deafblind people in different parts of India particularly in the rural areas as 80% of India's population are in the rural areas.

So the need of the hour was to develop professionals by providing training, which would be culture specific and ideally suit the needs of urban as well as the rural population. This vision and mission of Ms. Beroz N. Vacha (founder director of Helen Keller Institute) was fulfilled by the joint initiative of Helen Keller Institute and Sense International India in the year 2000.

Extensive technical inputs are provided by faculties within the organization from all over India as well as from INGOs like Sense International (India & UK) and Hilton Perkins International. Attending workshops on different disability related topics also enriches their experiences.

In considering the unique needs of children with deafblindness and multiple disabilities, which poses extreme challenges to the educators, this training focuses not only on providing theoretical inputs but also provides "hands on" experience of working with children with deafblindness and multiple disabilities.

A distinctive feature of this training center is to have a residential facility for both the trainees and children under one roof, thus providing opportunities to the trainees to learn about the needs of the children in all areas.

Their day begins with the wake-up duty with the children (supporting the children in the daily living activities like brushing, bathing, dressing, undressing etc. first under the guidance of hostel staff and then independently) followed by attending lectures, placement in the classroom (also accompanying children in gym, O.T. room, swimming pool etc) then planning recreational activities for the children in the evening.

Frequent simulation sessions with blindfolds and ear plugs (in the shopping mall, using public transport or having lunch in a restaurant) are a common and salient feature of the training!

Without the experience of Community Based Rehabilitation or learning to mobilize the indigenous resources, the training would be incomplete, as the trend showed increasing number of trainees from the rural parts of India. So a placement in the Home Based Programme of a partner organization- National Association for the Blind has been initiated in the last five years where the trainees get the exposure of working with the families in the home setting. An extensive training in functional assessment of vision, hearing, motor, ADL is provided to make the training more holistic.

Years have passed by and with each passing year number of trainees admitted surpassed previous years number. In these eight long years Helen Keller Institute had already trained 98 professionals from different parts of India as well as South East Asia, like Malaysia, Nepal & Sri Lanka and another 23 are in the making! Amongst the professionals trained so far some went to their organization where they had a Deafblind programme, some initiated a Deafblind programme in their organization and there are others who are working in Helen Keller Institute for Deaf and Deafblind.

So, the sapling sown nine years ago has blossomed into a full grown tree spreading its branches in all directions. This is because it has been nurtured with great care and dedication by all – and especially by its parent organization HKIDB.

As the number of children identified with deafblindness and multiple disabilities is on the rise so is the need for special educators. So, we pledge to continue the journey with this in mind " ...and miles to go before I sleep, and miles to go before I sleep", no matter what hurdles lies ahead!

The sensory integration perspective and what it offers us in the field of deafblindness

David Brown, Education Specialist at California DeafBlind Services concludes his series about the senses – with the first part of an article about sensory integration

In this final two-part article I want to look at what I call ‘the Sensory Integration perspective’ and consider why I think it offers us a very helpful way of thinking about the children with whom we work. First, though, I need to explain a little about the term ‘sensory integration’ because it refers to three closely related but different things:

1 It is a neurological process that begins while a foetus is developing, so that sensory systems are already starting to function for the unborn child, producing responses and learning inside the womb that will continue after birth. We know, for example, that tactile sensory receptors in the lips of a foetus are working from 7 weeks gestation, and that a 16 week old foetus will self-initiate tactile stimulation, especially around the mouth area. The taste system begins forming from 8 weeks gestational age. The entire vestibular system is formed and working by 21 weeks gestational age, so that excessive movement and position changes by the mother can produce evidence of vestibular over-stimulation in the foetus. The entire auditory system is formed and working by 24 weeks gestation and at this age the foetus can exhibit consistent calming or arousal (and movement) responses to specific external sounds. As the nerve fibers carry information from several different senses, all at the same time, the brain processes them simultaneously so that the senses seem to function together automatically. In fact each sense is designed to develop in this way so that it becomes even more effective as a part of the ‘symphony of the senses’ than it is on its own. As a result, when this sensory integration is working well, for most of the time none of us has any conscious awareness of each individual sense working, and we are free to focus our conscious minds on higher order activities even though the combined input of all these different sensory impressions is providing a constant multidimensional flow of essential information to our brains. When everything is working well most of our sensory perception and processing works on ‘automatic pilot’, and only when there is an unexpected or unusual sensory input are we challenged to attend consciously to the information we are receiving through that specific sensory channel.

2 ‘Sensory integration’ is also a theory developed in the 60s, 70s, and 80s by Jean Ayres, an occupational therapist, to try to explain exactly how all the different pieces of information coming in from all the separate senses get connected and blended together so that we function effectively. Ayres was working with learning disabled children who were exhibiting certain concerning behaviours – they were distractible and inattentive, unusually over-active or under-active, clumsy, poor at handwriting, and other things that hampered

academic achievement. She emphasized the important role of the tactile, proprioceptive, and vestibular senses in providing a secure foundation for the effective use of the vision and hearing senses. She also examined the relationship between information coming into a person through their sensory systems and the way the brain interprets this information and then responds to it (with what are known as 'adaptive responses'). Ayres defined sensory integration as :

“... the neurological process that organizes sensation from one's own body and from the environment and makes it possible to use the body effectively within the environment. The spatial and temporal aspects of inputs from different sensory modalities are interpreted, associated, and unified. Sensory integration is information processing... The brain must select, enhance, inhibit, compare, and associate the sensory information in a flexible, constantly changing pattern; in other words, the brain must integrate it.”

3 It is a treatment approach (known as Sensory Integration Therapy) which Ayres derived from her theory, that looks at how sensory information is received by an individual and what adaptive responses they make. Since Jean Ayres died in 1988 these ideas have continued to be developed by other occupational therapists and physiotherapists trained in Sensory Integration Therapy. The approach now includes consideration of many related issues including sensory perception and sensory processing, motor planning, arousal levels and self-regulation of these, sensory overloading, and sensory defensiveness. These days many teachers and teaching assistants in the field of Special Education have become familiar with some aspects of the therapy technique by seeing it used with children and also by being required to administer parts of the therapy program themselves, although they rarely receive any training in the approach itself nor in the theory behind it.

Geegee Larrington has written an excellent chapter on Sensory Integration Therapy in 'Understanding Deafblindness', which provides a concise but comprehensive overview of the basic principles on which it works. In the limited space available to us here I want now to take a brief look at Ayres' theory and then at some aspects of the therapy approach that are especially relevant to children with deafblindness.

Sensory Integration Theory

Ayres drew on a number of disciplines including neurology, psychology, occupational therapy, and education, and based her theory on a number of assumptions – namely the idea that interactions between a child and their environment have a significant impact on brain development, that the brain is plastic (that is, capable of changing in response to external stimuli), and that

experiences resulting from sensory inputs and the child's responses to them influence the way that the brain changes.

Sensory Integration Therapy

The key principles of the therapy approach can be summed up as follows:

1 The Just Right Challenge – so that the child is challenged by the chosen activities but their success is guaranteed. This demands a good knowledge of the child, including things like their sensory perception and sensory processing abilities, processing time, movement skills, attention span, short-term and long-term memory, sensory preferences, and their confidence in themselves and in us.

2 The Adaptive Response – the child must adapt their responses as a result of these 'just right' challenges, and they learn from the new strategies they devise and so improve their functioning.

3 Active Engagement – the child must be motivated and want to involve themselves in the activity, so that they are, in fact, reorganizing their own brains. This means that we need to spend time identifying the motivators for each individual child and then using them in the activities. In our population of children the strongest motivators might be very subtle and quite difficult to discover, or they might seem very odd to us sighted hearing adults and not be what we would ever consider motivating at all, or they might involve behaviours that many would just describe as 'self stimulating' and only try to stop.

4 Child Directed – as a result of careful and skilled observation the therapist is directed by the child's preferences, needs, and current abilities. Continuing observation during the sessions should lead the therapist to increase or decrease the sensory and motor demands of the activities as appropriate so that points 1 to 3 above are respected at all times.

Ayres explained succinctly that:

'A sensory integrative approach to treating learning disorders differs from many other approaches in that it does not teach specific skills... Rather, the objective is to enhance the brain's... capacity to perceive, remember, and motor plan... Therapy is considered a supplement, not a substitute to formal classroom instruction...' (1972)

This emphasis on the process of learning, rather than just on the acquisition of new skills, fits in well, as Geegee Larrington points out, with the idea that education for children with deafblindness should aim to develop understanding of

concepts and not just teach skills. In her chapter on sensory integration in 'Understanding Deafblindness' Larrington includes a helpful glossary of terms and concepts used in this therapy approach (p. 248 – 251), which not only defines terms but also provides a lot of wise advice on how to behave with any child who has difficulties with sensory integration, for whatever reason. The specific objectives of sensory integration therapy can be listed as follows:

- To achieve and maintain an alert, calm state so that the child is not persistently tending to become excessively drowsy nor excessively over-excited but is in the best state for attending and learning.
- To promote the organization of the Central Nervous System (ie. the brain and the spinal cord), in other words facilitating that neurological process of sensory integration that I described earlier.
- To enhance the child's ability to regulate and adjust the sensations from their environment, so that no sensory system is under or over reacting to stimulation, and the child is able to attend to what they need to and to ignore what does not need conscious attention. This should also reduce the child's need to be persistently seeking out or fleeing from stimulation through specific sensory channels.
- To increase conceptual development, which could be considered as the ultimate outcome for educationalists.

Sensory Integration and the impact of deafblindness

It is important to remember that Ayres' theories and her therapy approach were not developed with reference to children with deafblindness or with significant multiple disabilities, and that there has been very little research on applying them to this population of children. The children with whom we work do not only have difficulties in integrating all the messages coming in through their sensory systems, they also have entire senses missing or hardly functioning at all, plus a range of other challenges that did not feature in Ayres' research, such as physical disabilities, seizure disorders, and significant health issues. So why do I think it is so important to know about Ayres' work and that of the other therapists who have developed it further?

a First of all, the focus on the tactile, proprioceptive, and vestibular senses gives us an invaluable way of looking at children with deafblindness and trying to ascertain what is really happening to them, what and how they are perceiving, how they are processing, and what is really motivating them. This helps to move us away from too exclusive a focus on the senses of vision and hearing, which has traditionally existed in the field of deafblind education.

b Experience has shown that the theory that these three sensory systems provide the foundation for effective visual and auditory functioning is very helpful in practice, even (or especially) for children with severe multi sensory impairments and a high level of medical and nursing needs. And the knowledge that we have gained from this experience helps us to prioritize better in our educational assessment and programming and be more successful in helping children to develop their visual and auditory and tactile abilities.

c Both the theory and the therapy approach use concepts like sensory diet, sensory overloading, sensory hierarchies, sensory thresholds, and arousal levels and self-regulation, all of which can help us to understand children's behaviour that otherwise would seem to be quite paradoxical or inexplicable. This helps to move us from too exclusive a focus on cognitive skills, which is very often found in the field of special education.

d The idea that each child has their own needs and preferences, and that these should determine and guide our intervention if only we have the skills and the patience and the willingness to see and to understand them, fits in well with the 'follow the child' approach of influential educational theorists in our field such as Jan van Dijk and Lilli Nielsen.

e We all have sensory strengths and areas of need, and we all experience certain kinds of sensory integration dysfunction at different times in our lives, and for different reasons. Ayres' approach puts a focus on 'people' rather than on 'people with disabilities' and so helps us to remember the common humanity (and the common challenges) that we all share with all children with deafblindness.

So here is a theory and treatment approach based on aspects of human experience and behaviour that are widely recognized even if they are not widely understood. Like all theories it is only good and useful if you use what works for you and the child and leave the rest, and there is growing anecdotal evidence that much of what Sensory Integration Therapy offers in terms of assessment and treatment has been of real benefit to many children with deaf-blindness. Geegee Larrington sums up the shift that has taken place when she writes that:

'The field of sensory integration, as practiced primarily by some occupational therapists, began in its classical form as a therapist-directed treatment in a therapy clinic with children at the high end of dysfunction. The sensory integration frame of reference, however, has evolved and has been applied to other diagnoses and infused into educational and home programming for children all along the continuum of dysfunction' (Understanding Deafblindness, p. 319)

But this is a controversial area and people within the field of deafblindness still argue over what exactly is meant by the phrase 'Sensory Integration Therapy', they insist that only a fully qualified occupational therapist can do it, and they also say that its use with children with deafblindness has not been researched so it should never be considered for them. But anybody can, and most people do, rock a child to get their attention, or hug them tightly to calm them down, or bounce them gently to arouse them and wake them up, and so on, and all those actions, and their anticipated outcomes, are part of the spectrum of activities in Sensory Integration Therapy. As Ayres herself said:

'What is rocking and being cuddled other than tactile and vestibular stimulation plus an interpersonal relationship?' (S.I. and Learning Disorders 1972, p266)

The second, and final part of this article will appear in the next edition in the Summer of 2009.

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EDbN

Major report on the needs of people with Complex Dependency Needs

Inclusion Europe (a European level organisation that campaigns for the rights and interests of people with intellectual disabilities and their families) has produced a major report on the rights and needs of people with complex dependency needs funded by the European Commission. This report explores the areas of life where people with complex dependency needs face discrimination or potential discrimination. It then makes recommendations on how these can be addressed by Member States and the European Institutions. The project included a comparative study of the situation in twelve of the European Union Member States. The representative of each country produced a report on their country and case studies highlighting examples of good practice. The countries that took part were Germany, France, the United Kingdom, Italy,

Spain, Poland, Lithuania, the Czech Republic, the Netherlands, Belgium, Sweden and Romania.

EDbN (the European Deafblind Network, a network of DBI) participated in the policy committee for this project and so was able to make sure the needs of deafblind people were included. This committee was able to comment on the findings and recommendations.

Recommendations for national governments include issues such as ensuring counselling is available for parents following prenatal diagnosis, not automatically excluding people with severe disabilities from work and employment and making sure that housing is available that is suitable to the needs of people with severe disabilities.

The report also calls for European level action including developing a European Commission Communication (a document which begins a discussion on an area of importance) on better inclusion for people with complex needs and severe disabilities in all European policies.

This report is now available for all of us to use in our work in our individual countries. If you would like a copy of the report and recommendations you can go to the Inclusion Europe website (link below) or you can email: Inclusion Europe [Secretariat@inclusion-europe.org]

<http://www.inclusion-europe.org/main.php?lang=EN&level=1&s=83&mode=nav2&n1=159&n2=781>

Lucy Drescher, EDbN

Acquired Deafblindness Network ADbN

7th International Seminar in Bergen, Norway

This year a record 201 delegates travelled to Bergen in Norway for the 7th International Seminar of the Acquired Deafblindness Network. The title of the event was “Activity, Ability and Participation; Acquired Deafblindness in all stages of life”.

Following the practice of linking the outputs of one seminar to the programme of the one which follows, ADBN has sought to create a consistency of approach from one event to the next. This year the programme focussed on subjects as

diverse as employments, haptonomy, Usher syndrome, families and communication; over 6 plenaries and 20 workshops.

In addition the choice of plenary speakers reflected moves towards ever greater participation and involvement by professionals who live with deafblindness themselves. This involvement also enables latest research and emerging best practice to be placed within the lived experience of those who are deafblind.

The growth of numbers of people attending the event – numbers of delegates have more than doubled in the last 6 years – has led the Co-ordinating group of ADBN to change the name of the event from a seminar to a conference in 2010. This reflects the change over the years from an informal gathering of small numbers of people into a larger, more formal event.

The importance of the bi-annual gathering of practitioners and people with ADB has also led to a broadening of activities associated with the event. This year the Executive Committee of EDBU were invited to use the facilities of the seminar for their meeting and representatives of ADBN and EDBU met after the seminar to discuss ways in which their respective organisations can foster and develop closer working links in the future.

In addition, commencing in 2010 the Usher Syndrome study group has asked to have its pre-conference gathering attached to the ADBN event, signalling closer links between these 2 groups.

Attention now turns to 2010 when the 8th International Conference of ADBN is due to take place in Aalborg from 29 September – 3 October 2010. Note the dates in your diary now!

Ges Roulstone
Chair, ADBN

“Perfect days...”

So says Gill Morbey, of Sense Scotland about the “Listen2Me” event

We had the great privilege of hosting Listen 2 Me 4 from the 22nd-27th August. These wonderful events, organised by parents, have been hosted in Italy, Denmark, Catalonia and now Scotland. It was five perfect days of discussion, learning, fun and tears.

It was a joy to meet families from Catalonia, Spain, Czech Republic, Slovakia, Italy, Poland, England, Wales and Canada. The programme included practical activities in the arts, stress management, advice on after school provision and group homes led by Peter Fasung from Slovakia, Dr Joe Gibson discussed risk in outdoor activities and there were plenaries from Paul Hart on The Art of Being, David McCluskey on music and William Green on the importance of international working. We were lucky enough to be joined by Jenny Fletcher who supported our own staff with the children and it was a privilege to welcome Denis Loli from Hilton Perkins.

Ricard Lopez, with other parents, led workshops on the hopes and dreams of families. There was no surprise that mothers and fathers share the same dreams for their children, wherever they come from, and these wishes were hung on our wishing tree, that had been made by the Scottish siblings group, especially for the event.

Ursula Heinemann, Sabine Kersten and Gillian Foster led the brothers and sisters programme and presented a wonderful DVD from the previous Listen 2 Me in Salou. Graham Hicks led a panel of young deafblind adults who told us about the things that are important to them.

As you might expect the social programme consisted of whisky tasting, bag pipes, Scottish dance and music from around the world. All the entertainment was provided by Sense Scotland staff or deafblind people themselves and it was wonderful to host the final dinner at TouchBase, our new centre. William entertained us on the last night with a number of songs, including 'Perfect Day' and I would recommend the Canadian team led by Loney Hudson as a great country rock trio.

Huge thanks to everyone involved and we wish our friends in the Czech Republic all the best for Listen 2 Me 5 from everyone in Sense Scotland.

The information from the conference is posted on our website www.sensescotland.org.uk and DVD's are available by email info@sensescotland.org.uk

The Siblings Network

Sabine Kersten reports

We had a great week during Listen to me, which was held in Glasgow at the end of August. Although we were a small group we had good fun!. Starting the week

we went bowling and the end of the week some of us were climbing! The main reason to come together was to talk about some concerns siblings have on their mind. The group was very honest and open and I would like to thank all the participants for that.

The meetings we had again showed that more services for siblings are needed. This does not mean that it should ONLY be about serious discussions. It is more important that siblings come together and have fun so they get to know each other. The talking can come later.

The next event where we will be present will be the European Dbl Conference in Italy next year.

Get in touch and come and join us! You will be very welcome!

Sabine Kersten
siblingnetwork@gmx.net

Usher Study Group

Marylin Kilsby reports:

Following on from the highly successful Usher Study Group in Perth, Western Australia, we are already making plans for the next Usher Study Group. We will be hosting the Usher section of the Special Interest Day at the Dbl European conference in Senigallia, Italy, in September 2009 and we may hold an USG pre-conference to the same event as well.

I am looking into starting an USG e-group as a way of remaining in contact between USG meetings and also keeping up to date with current thinking and research on Usher issues.

Get in touch if you would like to join us.

marylin.kilsby@sense.org.uk

Co-Creating Communication:

Theory and Practice with congenitally deafblind people

Leeds, Wednesday 8th – Saturday 11th October 2008

Report by Asun Snow

The Deafblind International Conference, Co-Creating Communication with Persons with Congenital Deafblindness, took place in Leeds in the UK. It was organised by Asun Snow from Sense with scientific content from the DBI Communication Network. At the Gala Dinner held on the last day of the Conference, Asun Snow said that it had been a longstanding dream for this conference to be hosted by Sense in the UK. That dream was finally realised when, all the planning having been done and the final programmes set, the Speakers and over 160 Delegates from more than 17 countries descended on the North of England and took their seats at the Royal Armouries Museum in Leeds on the morning of 8th October 2008.

The practical aim of the Conference was to describe and disseminate the latest theoretical ideas around developing communication with congenitally deafblind people. However, the Organisers hoped that the ideas which came out the discussions would permeate practice for many years to come. This was a theme which was highlighted by Bob Snow in his opening remarks to the Conference when he commented that such gatherings of people, thoughts and ideas are meaningless unless it makes a real difference to the practice of each and every Delegate once they get back to their own situations and a real difference to the lives of deafblind people.

Jacques Souriau, from the DBI Communication Network, said in an address to the delegates that people with congenital deafblindness are extremely vulnerable – communication is a big challenge for them and their partners. But they become much less vulnerable as a result of the dialogue that continually takes place between deafblind people, their families and professionals.

The countless numbers of fabulous dialogues that took place during this Conference was one good example of how that can happen.

The conference addressed four key aspects of human communication. These four themes were selected because they helped to describe how life experiences

and emotions form and flow dynamically over time in the encounter between individuals and the external world. The four themes were:

- Dialogicality
- Joint Attention
- Gestures and Mimetics
- Language

Each theme was opened up from a theoretical perspective by a leading thinker in each field: Ivana Markova, Dr. Peter Hobson, Susan Duncan and Kari-Anne Selvik respectively. These key note speakers clearly built on ideas from previous Dbl Network conferences, and each outlined recent thinking and gave unique insights into how these themes influence the way in which any human develops communication and language. They also brought new knowledge into our field, which was inspirational and certainly indicated some of the routes for future explorations in communication and congenital deafblindness.

Each day the ideas from the speakers were responded to by a member of the Dbl Communication network in an attempt to understand how these ideas impact on communication with congenitally deafblind people and thus, trying to grapple with real practical solutions to the challenges. This led to very exciting, and often fast-moving discussions and reflections involving speakers, responders and the audience at the end of each morning session.

The afternoon workshop format provided the opportunity to discuss the subject matter on a more intimate level. It allowed illustration of the central themes through clear examples from video. These workshops were very interesting and inspiring – indeed so much so, that many of the groups ran out of time every day! Each day was completed by a series of workshops mainly delivered by Sense and Sense Scotland staff but including a wonderful presentation from Andrea Scheele from Germany. Although these workshops did not specifically tackle the four conference themes, many presenters did relate their own work directly to the conference.

The Conference highlighted the fact that Practitioners – which include all partners of deafblind persons – need Theory because it enables them:

- to understand what they do
- to be able to reflect and discuss their own practice
- and to be able to cultivate the very specific learning conditions that deafblind people need to show their communicative competences.

Ivana Markova, Peter Hobson and Susan Duncan also commented on the important contributions that deafblind persons can offer to the knowledge on how all human beings develop and communicate.

The 'big dream' of the Conference was that the ideas and thoughts that emerged from all the presentations and workshops over the week, would spark a great

many dialogues which would, in future years, inspire improvements in communication practice in the UK, across Europe and right across the world. In her remarks at the Closing Ceremony,, from the Communication Network spoke about the need for younger and new people to be involved in the journey which is taking forward the understanding of persons with congenital deafblindness and it was promising for the future quality of deafblind services to follow the eager discussions in the breaks and in the workshops. She observed a lot of curious glimpses in people's eyes which seemed to indicate 'this is very interesting; 'this is not quite easy'; 'but I want to understand'; and 'I want to understand how I can bring these new thoughts into practice with the deafblind persons I work with.'

Jacques Souriau described our increasing understanding of communication with persons with congenital deafblindness as a journey and Inger summed up the Conference well when she said:

'What a great journey into knowledge of communication and congenital deafblindness we have been on!'

I think it has been an excellent example of how dialogues between researchers and practitioners co-create new meaning – and indeed how much we need each other'.

Finally, remember to buy a ticket for the next part of the journey. The destination is Paris in the Spring of 2010.

The Deafblind capital of Jordan is Salt!

Jacques Souriau recounts his thoughts about a very special place... the Holy Land Institute for the Deaf and Deafblind

According to the very special Deafblind geography, deafblind capitals are not the same as the administrative ones. Deafblind capitals are Sint-Michielsgestel, Perkins, Osimo, Poitiers or Allborg, rather than Amsterdam Washington, Rome, Paris or Copenhagen. Until recently, I did not know about the Deafblind capital of Jordan. I did not even know that there was a program for the deafblind in this middle-eastern country nestling between Iraq, Saudi-Arabia, Israel, the West Bank and Syria. I knew about the magnificent lost city of Petra and the splendid camel-rides of Lawrence of Arabia in the Wadi-Rum desert, but nothing like a Jordanian Deafblind Program.

In October 2007, during my lectures for the Master on Communication and Congenital Deafblindness at the University of Groningen, I met Aline Hanning-Zwanenburg, a Dutch student. It was quite a surprise for me to hear about her very active involvement in a new program for children with congenital deafblindness in Jordan where she lives. I was all the more happy to hear about this as my wife and I were working at arranging a two-week holiday in Jordan in April 2008. Eventually, we decided to take advantage of this trip to meet Aline in her school and help her with her thesis (which was supervised by my colleagues, Anne Nafstad and Inger Rodbroe). These circumstances gave me the occasion to spend three days in the “Holy Land Institute for the Deaf and Deafblind” (HLID), the organization that runs the program for the Deafblind in Jordan.

The “Holy Land Institute for the Deaf and Deafblind”

I know now that the deafblind capital of Jordan is Salt. In this city, 30kms from Amman, HLID runs a school for the Deaf that was established in 1964. It offers education and boarding to approximately 145 students, ranging in age from 4 to 20 years. Some of them have other disabilities in addition to deafness, such as deafblindness. It offers four levels of education, from kindergarten through elementary and preparatory schools to secondary level. After secondary school, there is the option to pursue a college or university degree in the regular system, outside the Institute, with the assistance of a Sign language interpreter. Vocational Training is also provided: carpentry, mechanics, embroidery, sewing, weaving and, most impressive, an earmould laboratory where students can be trained for the production of earmoulds.

HLID is also very active in promoting staff development activities related to various disabilities in the Arabic language through the STRIDE program (‘Salt Training & Resource Institute for Disability Etc’). It reaches countries like Syria, Iraq, Yemen, Egypt and the West Bank. It organizes and conducts Arabic and Jordanian Sign language courses on different levels for teachers, parents and other family members of deaf children and it also trains professional interpreters. The Institute hopes that one day it will train people in the care and education of Deafblind children and young people from throughout the region.

A department for deafblind within an institution for the deaf

The deafblind department first opened its doors in September 2001 for four students ranging from 7 years of age to 15 years, three boys and one girl, all of whom are completely blind; one is profoundly deaf and two have some residual hearing. One of the boys does not have a hearing-loss but presents with a speech impairment. In October 2008, two young girls joined the program. At the time of our visit, day activities were organized in a small building next to the school, but the deafblind department recently moved to a bigger facility, enabling further expansion.

The deafblind students benefit from a special educational program, but also use some of the same facilities as the deaf students, for instance the Art and Crafts room and the pottery classes. Meals are provided within the program for the deaf and there are options for boarding in the deaf students' dormitories, depending on the level of independence of the student. This organization provides possibilities for integration and opens up a world of communication opportunities that would not have occurred within the setting of the deafblind department alone. At meal times and after-school hours, deafblind students are accompanied by deaf ones. They have deaf friends and are naturally exposed to social rules. Conversely, it is an occasion for the deaf students to take on responsibilities and provides great opportunities for them to learn to share their lives with people who need them, their support and their friendship. The impact is particularly visible on language development: one of the deafblind students who had a basic level of Jordanian Sign language before he moved to the boys boarding house several years ago, developed his linguistic competence tremendously through friendships with his deaf peers.

Aline Hanning-Zwanenburg, a Dutch Special educationalist, lives in Salt and works in the deafblind department where she plays a vital role. She is the one who trains the professionals and gives advice to the families. She is very much supported by the management of the school and benefits from equipment like camcorders and video recorders that are essential to staff training activities in the field of congenital deafblindness. She is passionate about her work and shares that passion with hearing and deaf colleagues and students alike. Staff members are very dedicated and enjoy the opportunities of development they find in their contacts with congenitally deafblind children.

In this community made of a welcoming school for the deaf, a warm and expert professional staff, excellent supervision from Aline, the deafblind children are happy and develop in a very natural and expert way. The blend between the local potential and the contribution of a highly trained professional provides a very creative context. The "Holy Land Institute for the Deaf and Deafblind" in Salt (Jordan) is one the best places for deafblind children in the world.

Making friends, music and meeting reindeer in Lapland!

Murray Farquharson shares his holiday diary – a cultural feast!

I was invited to attend The Youth Summer Camp in Lapland by Seija Troyano from The Finnish Deafblind Association. I have been a member of Sense

Scotland a deafblind charity which supports families across Scotland since I was a little boy of 8 years old. I am now 32 years old and have had some wonderful experiences with Sense Scotland meeting deafblind people from all over the world.

I want to tell you about the experiences I had during this trip and about the people I met. I was supported by Jackie Reid, Sense's Family Advisor during my trip. We left Edinburgh Airport on 4th August and flew to Helsinki via the new Terminal 5 Building at London Heathrow. Sanna Tuomaalo, who was one of the main organiser of the trip, met us and she took us to our first accommodation. We stayed at Iiris House, the Finnish Deafblind Association's Headquarters in Helsinki. I thought this was a great building, it had tactile information to help a deafblind person move around the building independently.

We started our trip on Tuesday 5th August and boarded a bus for our long drive up to Lapland. We stayed 1 night at Oulu to break the journey and this gave me a chance to have my first Finnish pint of beer! In the evening the entire group met for dinner, which gave us time to get to know each other. We had 2 Interpreters throughout the trip and that really helped me to be able to speak with the other young people.

We arrived in Lapland on Wednesday 6th August, our bus driver Arimatti had to avoid Reindeer that were standing on the road. We stayed in the Hullo Poro Hotel, again there were Reindeer walking around the streets, they had bells round their necks, which made a lovely sound. I shared a room with Jaakko. He was an easy going room-mate. I was the 'early bird' getting up before everyone else and getting myself showered and ready for the day. I enjoyed the massage chair in the Hotel before breakfast. The food was delicious, so were the drinks. I tried different Finnish Beers, such as Karjala, Koff, Karhu and Lapin Kulta – I called this one 'Santa Clause Beer'. In fact I met Santa Clause at the Arctic Circle! That was fun; when we got inside there was a snow machine and I was able to feel the cold snow it was blowing out. I got to meet Santa Clause and felt his clothes and beard. He and I had a good talk together.

On Thursday 7th we went for a Sauna and Swim. That was great fun. There was a group of us splashing each other in the Spa. I was a bit worried about not wearing swimming shorts in the Changing Room and Sauna. This does not happen in Scotland. Everyone was so proud of me for giving it a go! They were saying I was now a Finnish Man. In the afternoon we went up a mountain in a Gondola Lift. The group did some activities there, we had a Tug of War competition and I was the 'anchor man', I think my team won! One of the young people, Jonne, did a 'signed' 'Yoddle' about Reindeer. At the bottom of the mountain I found a big wooden swing, which was a surprise. I have loved the feeling of being on a swing since I was a little boy, so I had some fun on this one. On Friday 8th August we visited the Polar Speed Centre. We got to feel the fur of the husky dogs. I stood on a sledge and felt the skis below my feet. We sat in a wooden hut, by an open fire and listened to the Boran Drum, we were offered

smoked reindeer meat and herb wine. It was a Lapland Baptism, so now I was not only a Finnish Man but a Laplander too! My favourite bit of this day was “kissing a Reindeer”, I put a biscuit in my mouth and the Reindeer came and took it out my mouth. It was the first time I had been able to feel the fur and antlers of a Reindeer; they were so soft to touch.

On the Friday night we had a Farewell Party. Seija had arranged for me to borrow a Russian Accordion from a man called Aatos Ahonen. I played some Scottish Music for the group. During this party we did a Drama Production. I was invited into this by some of the young people. We pretended we were in a Sauna but they did have their swimming trunks on for this! Jonne presented me with a Finnish Hat; the group had collected money to buy me this gift, which was very kind of them. Jackie and I also received a Kuksa Wooden Cup as a gift, it feels lovely. I gave the group some gifts too. I brought Scottish Shortbread and copies of my Accordion Music CD, which I am sure everyone will enjoy.

Throughout the trip we had daily planning meetings with the group and one day we were able to learn more about the new Interpreting Service for deafblind people. We were able to speak to Sense Scotland’s Outdoor Tutor by video link, Dr Joe Gibson. He was in Sense’s Scottish Office speaking to us in Lapland, and he was using the Interpreter who was sitting in her office in Helsinki. Joe asked me “if there was any beer left in Finland, that gave us a laugh”!

We travelled back to Helsinki on Saturday the 9th August – it was a long bus journey but it was no problem, we had lots of stops for drinks and food.

I hope everyone, yes... everyone, enjoys reading this article, as I have enjoyed representing Sense Scotland on this fantastic trip to Finland. I hope to meet up with my friends in the future; maybe they could visit us in Scotland!

Romania – the ‘rights’ agenda

In Romania the Association of Deafblind Adults and Sense International (Romania) have been working partnership to increase the capacity of Deafblind people and their organisations to fight for their rights.

The very successful PHARE project has identified more deafblind people and has developed 3 courses: one on organisational management, one on project management and writing skills for application and a third was a Legal Counselling session for a group of 10 deafblind people to acquaint them with the law in respect of their disability.

All these activities were a mixture of practical and theoretical activity.

Teodora Seiciuc

The Norman Brown Prize

Evaluating the use of equipment in multi-sensory environments

The University of Birmingham (UK) programme in Multi-sensory Impairment (Deafblindness) has just awarded the first Norman Brown prize for an excellent investigative project which also has wide application – internationally and with both adults and children. This prize-winning project is by Gary Hyndman (Education Service Manager at Bourne Resource Centre, Sense, UK) and here is an abridged version prepared for publication by Liz Hodges, tutor on the University deafblindness programme.

Norman was known across the world in the field of deafblindness, for his work with families. In his later years, he worked at the University.

Gary describes how a systematic evaluation of curriculum areas can be undertaken and the impact this can have on teaching and learning when recommendations are put into place. Gary writes about sensory development work, but this method could apply to any area of learning.

Introduction

When Bourne resource centre (a college for deafblind people run by Sense) was set up, the resource most staff wanted to meet students' needs was a Multi-sensory room (MSR). A multi-sensory room is a space set aside which can be used with sensory stimulation equipment, such as different colours and movements of lights, and it can be very technologically based, so that it can react to the learner's moves. The room itself is usually devoid of other stimuli, so can be made dark and quiet to highlight the sensory input. The one at Bourne is a withdrawal area where staff bring boxes of equipment, such as instruments, lights, fluorescent items and it also contains expensive light based equipment such as bubble tubes.

In reality the room did not live up to the high expectations and those of the staff team. Initially resources had been purchased based on an ideal of what a MSR should look like rather than what students required. The curriculum did not mention work in the room, and staff tended to view it as extra curricular, and non educational. No meaningful assessment was carried out in relation to programmes in the room, although assessment is key to the successful adaptation of the room in relation to a clear understanding of an individual's needs. In the absence of training staff found their own way and this led to

inconsistency. Subsequently sessions were dropped as staff reported students losing interest, withdrawing or displaying an increase in challenging behaviour. To evaluate this issue effectively, I looked at the theory behind multi-sensory rooms, and then undertook two case studies of students, along with consultation with key staff. Thus I gained an understanding of the students' experiences and from this, framed recommendations to change practice.

The theory

Pagliano describes a multi-sensory room as a space where stimulation equipment can be controlled, intensified, reduced, made responsive to individual students, and matched to individuals' motivation and educational needs". While Bourne's equipment included technologically based sounds and lights, controlled stimulation can happen with a torch and a tambourine, or whatever is available locally. Approaches to the use of the room include using it 'just for fun' without intervention, (a passive approach) and using it for learning (a developmental approach) (Bozic). If staff assume the equipment provides all that is needed without support, it can be effectively a 'dumping ground' or alternatively, the influence of sophisticated technology can inhibit use of the natural sound, lights and other stimuli in the real environment, perhaps because staff do not know how to use it. It is disputed whether the MSR can equip learners with skills which are transferable into other environments. In one observation I was shocked to find the staff using all the highly stimulating equipment at the same time. The result was total confusion and sensory overload for the learners using the room.

The investigation

My investigation used a process approach with personal experience and case studies, more important than statistics or an end product. Two learners were the key focus; Robert, who has limited vision in only one eye, and is severely deaf, and Jamil, who has a cortical visual impairment, with some light/dark perception and a moderate/severe hearing loss. Both have developmental delay. The college management, staff team and students' parents all agreed to take part. Students were not able to give formal consent, but if they showed anxiety or distress the project would end. Students' identities have been disguised. Firstly, I analysed four months of teaching documents, examining how the MSR met the needs of the students. I questioned how sessions were structured, staffed, resourced and what programmes were actually used. I found that sessions addressed some aspects of sensory needs, but were insufficiently focused, with little structure, that students' activities were not based on assessment and were not individually designed to improve sensory function. Then I carried out observations of four sessions. I recorded who was present, the session's length, on which assessments it was based, and its aims, as well as how resources met individual need, and whether the student enjoyed it. In

Robert's case it was clear a range of strategies were being used, but a number of staff and students used the room simultaneously. This busy environment was a confusing experience and no individual support to explore the resources was provided. Appropriate activities were offered but were carried out in an inconsistent manner. This made it difficult for Robert to concentrate or to develop understanding of cause and effect. Jamil worked one to one in the MSR for thirty minutes. The tutor recorded an assessment, using auditory stimuli from a sound bank established after previous sessions. The activities were challenging, but also relaxing, and encouraged him to attend and show preferences. Finally I undertook interviews with four staff to understand their perceptions of the value of the MSR. I asked them what they used the room for, whether they considered students benefited from it and whether they were trained in using the MSR. Staff saw it as very valuable, but they used it as a space for relaxation and stimulation, only one mentioning education or functional assessment. They all had some relevant training, but no-one had any specific training in MSRs. They considered that Jamil and Robert enjoyed their sessions, but their evidence was unclear.

Changes

I planned changes based on this information. I devised a target setting sheet (Individual Sensory Programme or ISP) which indicated what a student could do now, and what they could do with support; which could offer structure and guidance to tutors. I delivered a training session and produced guidelines on resources and activities within the MSI and on support for individual students, including that ISPs needed one to one work. To monitor developments I repeated the observations and interviews.

In the observations, improvements were evident. Structure and communication increased, the sessions focused more on individual need and developing sensory skills, and activities were more challenging.

Since Robert began to work one to one on his ISP he has generalised skills to the rest of his environment, using more visual behaviour, and whereas he had been reluctant to use trailing, one ISP target, to trail a fluorescent tactile strip in the MSR, has led to him trailing from room to room using an identical strip, across the college. Jamil worked on visual attending, but then a sensory story was introduced to extend his interest and concentration. This allowed him to use the visual skills he had been practising. This also demonstrated a new balance between the previously lack of direction and an overzealous approach, denying the student independent exploration and discovery.

Tutors also showed a significant improvement in understanding both theory and practice in the MSR, giving examples of increased sensory attention from students and their own better understanding of teaching and learning.

What's happening now

My perception had been that the MSR may have been misused but I found good practice to build on, and staff who were very positive about the resource. There was confusion about whether they saw the room as predominantly for fun, (passive), or for development (interactive). The organisation had of course previously failed to provide appropriate training to support the use of the MSR. When this was identified and remedied, the staff took it on willingly, developing a new approach, with joint ownership of improvements implemented through a positive approach in the staff team. In addition to improvements in assessment and more challenging targets, this had a significant impact on morale as staff are now involved in work for which external professionals had previously been employed.

When the college opened I was very positive about the MSR as an excellent resource; but following observations and staff comments I questioned its value. This investigation helped put the problem into context and provided a way forward. I am now working with other managers of Sense colleges to share what we have learnt and hope that we will build a motivated group of trained staff working to ensure the MSR is a valuable resource for all students whatever their abilities and needs.

References;

Pagliano P (2001) Using a Multisensory Environment; A practical Guide for Teachers London; David Fulton Publishers

Bozic (1997) Constructing the room; multisensory rooms in educational contexts European Journal of Special Needs Education Vol 12 no 1 Pg 54-70

If you would like to read this project in full, please contact Liz or Gary
Gary.hyndman@sense.org.uk and Liz Hodges e.m.hodges@bham.ac.uk

FIRST ANNOUNCEMENT

World Federation of the DeafBlind, WFDB 9th Helen Keller World Conference and WFDB 3rd General Assembly

Imperial Royale Hotel, Kampala, Uganda, October 22 – 27, 2009.

Hosting organisation: The National Association of DeafBlind people Uganda, NADBU

CRPD, changing the lives of persons with deafblindness

CRPD is a human rights instrument. How can we use this instrument to ensure that the rights of persons with deafblindness are respected and enforced.

website: www.wfdb.org

Venue: Imperial Royale Hotel in Kampala Uganda, a totally new five-star hotel with excellent facilities for our conference. The hotel has 270 rooms and the Imperial Group has two other hotels nearby from where they will provide free transport to the Conference hotel

www.imperialhotels.co.ug/improyale_overview.

http://www.imperialhotels.co.ug/grand_imperial_overview.

www.imperialhotels.co.ug/equatoria_overview.htm

Conference fee

The conference fee will be 200 euros per person for deafblind participants, 200 euros

per person for interpreters/ assistants and 250 Euros per person for all others, which will include welcome reception, conference material, 5 days lunches, 5 days coffee/ tea breaks, mineral water during the conference.

Delegates' responsibility: excursions, conference dinner or any other dinner, airport transfer

and transport to conference, visa, vaccination and other personal expenses.

Sponsored participants

WFDB will sponsor a limited number of participants from developing countries.

Call for abstracts: Abstracts of plenary presentations or workshops covering one of these areas, can be sent to the WFDB office before

February 1, 2009 see address below:

Lex Grandia, Snehvidevej 13, DK 9400 Noerresundby , Denmark

phone: +45 98 19 20 99

fax: +45 98 19 20 57 e-mail: lex.grandia@mail.dk wfdb@wfdb.org

Country News

Australia

UN Convention on the rights of persons with disabilities

With the Convention now in force, the UN has published 'Disability Treaty Closes a Gap in Protecting Human Rights' to put it into the context of the other human rights treaties and 'The Convention is in Force – What Next?' identifying what is expected of ratifying countries. For more information, visit UN Enable at <http://www.un.org/disabilities/>.

The Australian Government has welcomed the entry into force of the Convention and will begin consulting the States and Territories on the Optional Protocol to the Convention. For more information about consultation of Australia's possible

ratification of the convention, visit <http://www.ag.gov.au/disabilityconvention>. The Australian Federation of Disability Organisations (AFDO) has been commissioned by the Commonwealth Government to conduct a series of national consultations. For more information, go to <http://www.afdo.org.au/node/228>

Disability strategy for Australia's aid program

AusAID has established a 'Disabilities Taskforce' aimed at developing and overseeing a disability strategy for Australia's Aid Program. Supporting this push for mainstreaming disability in the aid program, Parliamentary Secretary for International Development Assistance, Bob McMullan has said he wants Australia to be world leader on disability in development over coming years. Members of the Australian Disability & Development Consortium's (ADDC) Policy Advisory Committee have met with Bob McMullan and AusAID and a Key Reference Group has been established to consult on the draft disability strategy during July. For more information, visit ADDC (Australian Development and Disability Consortium) at <http://www.addc.org.au/> or email pdeany@cbm.org.au.

Aids and equipment

Disability Ministers met in Sydney on 30 May to further negotiations towards a new Disability Agreement and confirmed that new funding has begun flowing immediately to ease the nationwide demand for disability services. State and Territory Ministers agreed to provide \$900 million, on top of the Australian Government's \$1 billion, and in addition to indexation. This reflects an election promise made by Federal Labor.

Ministers also agreed to deliver national consistency for the provision of aids and equipment. Currently aids and equipment schemes sit outside the Commonwealth States & Territories Disability Agreement and are fragmented, with large gaps and inequities.

Building access resources

The Human Rights and Equal Opportunity Commission (HREOC) is currently working with the Australian Building Codes Board (and with a range of industry, community and government bodies) to develop a Disability Discrimination Act Disability Standard on Access to Premises. HREOC has published two new resources on its website – 'The Good, the bad and the ugly' (updated version at http://www.hreoc.gov.au/disability_rights/buildings/good.htm) and 'Guidelines on

access to buildings and services'

(http://www.hreoc.gov.au/disability_rights/buildings/guidelines.htm)

Louis Braille bicentenary

A list of ideas for promoting the bicentenary throughout the coming months in Australia is available from the RIDBC Renwick Centre by emailing mike.steer@ridbc.org.au. National Braille Press, a non-profit printing house in the US, has secured the domain name <http://www.louisbraillebicentennial.com> for 2008 and 2009.

South Pacific Educators in Vision Impairment (SPEVI) Biennial Conference:

The SPEVI 2009 Biennial Conference will be held from 6 to 9 January 2009 in Adelaide. The theme of Challenges and Choices will focus on vision impairment, adaptive technology, early intervention and partnerships. The Call for Papers closed on 29 February 2008. For more information, phone Jessica Bosnakis of All Occasions Management on 001 61 8 8354 2285 or email Jessica@aomevents.com

Senses Foundation Celebrates Deafblind Awareness Week – Touchy Feely

One of the events was a sensory sculpture exhibition by renowned sculptor Robert Hitchcock held in the foyer of Central Park in Perth central. 10,000 people walk through the foyer of this building every day so the exposure was sensational.

Our promotional material was absolutely spectacular and many people took the opportunity to touch and feel the exhibits while they learnt a little about Senses Foundation and deafblindness.

“Hob Nobbing” with the Governor

A group of people who are deafblind, their families and staff of Senses Foundation were invited to morning tea at Government House, by Senses Foundation patron and Governor of Western Australia, Dr Ken Michael and Mrs Michael.

Feedback from those who attended was that His Excellency and Mrs Michael were so gracious and interested in the personal circumstances of each person and their family and confirmed their commitment to the deafblind community.

England

The big move for Sense

The new building is now even more deafblind friendly!

When two schoolgirls arrived to have some “work experience” at Sense last summer they found themselves being commissioned to write an article about the organisation’s new London base! Chelsey-Marie Herron-Cameron and Yumna Naveed Nayab tell us more...

Sense UK has now moved from its Finsbury Park office to a new one in Kings Cross. The building officially opened on the 19th February 2008 following a swift and smooth move. The staff settled in straight away and most people have really positive views about it.

Nick Southern who has Usher syndrome works here and says, ‘It is tidier and there is less clutter on desks and shelves and more space. There is a special navigation path for deafblind people to walk round the building; it contrasts with the blue carpet and black tactile border.’

Why Sense moved

One of the main reasons for the move was the lack of physical access for wheelchair users. In old building the lift only went up to two of the three floors and this provided difficulties for the disabled members of the staff or visitors, as the top floor was inaccessible to them. Now in the new building there is a lift that can access all areas and the lift communicates verbally, announcing which floor you are at. This is helpful for people who are blind.

The old office was congested, hot and uncomfortable. There were issues over natural light. This new office benefits most staff as it has a lot of space and there are some very valuable meeting rooms. Every door in the office has Braille on it so it is easier for the deafblind people to get around and know their way.

The Office now houses the Chief Executive's Office, Fundraising and Community Support and Information. The Library in the new building contains around 4,000 items which are easily accessible and the library staff are always willing to help! We wanted to get a feel for what it would be like for someone with limited sight and hearing to use the building so we decided to simulate the situation by wearing a blindfold and headphones over our ears. At the start it was really scary and when something unusual or out of the ordinary happened it was quite a shock and sometimes it even made you scream. However, we found the building less frightening as we moved around.

The Braille on every door helps you find your way around and the banisters on the stairs help you know where you are and prevent you from falling.

This experience was very enlightening and helped us relate to people who are deafblind and see a little bit about how life is for them. Trying this out made us admire and respect them even more! The building is really helpful for deafblind people, but also for everyone else.

We spoke to Lydia Turner, who is the PR Executive and she said 'I think that it has made for a nicer working environment. I think the 'breakout' room where everybody can go for lunch is a great idea. It means there is much more opportunity to communicate with people from different teams in a relaxed environment. I also think the walkways are much clearer for those with visual impairments.'

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Scandinavia

The Nordic Staff Training Centre for Deafblind Services (NUD) is becoming part of a bigger organization

Two years ago, the Nordic Council of Ministers started a process of reorganizing their institutions working with social service and politics. The result of this reorganization is that four institutions will become one: "Nordiskt Välfärdscenter (NVC)" (A temporary title in English: Nordic Centre for Welfare and Social Issues).

The three other institutions are:

NSH (Nordic Cooperation on Disability)

NOPUS (Nordic Education Programme for Social Service Development)
NAD (Nordic Centre for Alcohol and Drug Research)
“NVC’s” main office will be located in Stockholm, Sweden, but NUD (our new name will be “NVC Danmark”) will be a daughter institution still situated at Dronninglund Castle, Denmark.

The consequences for us management wise are that we no longer will be an independent centre answering directly to the Nordic Council of Ministers. Rather, we will have a director who will be situated in Sweden and running three offices: one in Sweden, one in Finland and one in Denmark. The director will be the person with the direct contact to the Council of Ministers and the politicians. Aside from the change of name and structure, the plans right now are that “NVC Danmark” should continue being a staff training centre for people who work within the field of deafblindness. Hopefully, we will, along with the whole field of deafblindness, be able to convince our new director, the new board, and the politicians that a centre like ours is unique and needed. Right now we are trying to be as proactive as possible, and working on finding out how the field of deafblindness can benefit from this new organization that we will be a part of. One of the main goals of “NVC” is international collaboration which we fortunately can say that we already have on our agenda. So you will hear more from us in the future!

Lasse Wehner Winter

Italy

News of a research project

Towards a linguistic description of LISt (Tactile Italian Sign Language)

Lega del Filo D’Oro and the Psychology Department at the University of Milan-Bicocca are jointly investigating the variation between LIS (Lingua dei Segni Italiana, Italian Sign Language) and the tactile sign language based on it, namely LISt (Lingua dei Segni Italiana tattile, Tactile Italian Sign Language).

One fundamental way in which LIS and LISt differ is this: in LISt linguistic information can only be conveyed through the hands, therefore non-manual marking of grammatical import (for example, eyebrow raising or lowering) must be replaced in LISt by some other device (a new manual sign, a modification in intensity and/or rhythm of existing signs, extended pauses, etc.). LIS differs from LISt also in two other major respects. The signing space of LISt is reduced,

compared to the one of LIS. Presumably, this is due to articulatory reasons, since moving the hands while keeping contact with someone else's hand is physically demanding. The other difference is the fact that in LISt the language recipient can identify hand-shape only by touching the back of the utterer's hand. Since these two factors are likely to modify the basic values of two of the four formational parameters of signs (location and hand-shape), we plan to investigate how the phonology of LISt is affected.

One hypothesis that guides our project is that the solutions, spontaneously and subconsciously, adopted by skilled LISt signers to adapt LIS to the tactile modality can become the basis for a more effective training in LISt. Training in LISt is important, because the onset of blindness in deaf individuals is gradual and largely predictable, thus the perspective deafblind can be trained in LISt when (s)he still has a good visual residue, in order to be better prepared to cope with his/her future condition. In its turn, training based on the solutions adopted by skilled LISt signers may help to standardize LISt, thus fulfilling a need that is often expressed within the community of deafblind people. From a theoretically point of view, investigating the way in which the transfer from LIS to LISt takes place may help us to identify 'the resilient properties of language', those properties that are always found in communication systems whatever medium is used.

The project so far

The project started from the data collection phase: 5 deafblind subjects who are fluent in LISt visited Bicocca University for a one week elicitation session. About 25-30 hours of conversations between pairs of deafblind subjects were taped, with each conversation filmed from four different angles. Various elicitation techniques were used (storytelling, role-playing, "Guess the Celebrity" games, etc.)

In the longer term

Our long-term plan is analyzing and glossing all this material with the help of a LISt interpreter by using the ELAN annotation software. Currently, we are searching this material in order to identify, analyze and gloss those constructions that require non-manual marking in LIS, like wh questions and yes-no questions. We started our investigation from these constructions since they are more likely to differ in the tactile version of the sign language. We expect to have the first preliminary report on question formation in LISt by the first months of 2009. The next step will be analyzing how the phonology of LISt is affected by the tactile modality.

For more information contact info@legadelfilodoro.it

A New Director for Perkins International Programme

Steve Rothstein welcomes Sergei Sorokin...

It is a very special pleasure to announce the appointment of the new Director of the Perkins International Program, including our valuable Hilton/Perkins international initiatives (<http://www.perkins.org/international/>)

Our new director, Sergei L. Sorokin, will continue in the remarkable leadership exemplified by Michael T. Collins. Michael's grace, wisdom and interpersonal skills established this program and ensured a solid foundation moving forward. We will continue to support partners in 63 countries and expand the number of children, their families, their teachers and others we collaborate with in conjunction with our amazing staff, consultants, donors and international partners and under the leadership of our new director.

Sergei was born and brought up in Moscow, Russia. He was educated in Russia and received a Master of Special Education at Moscow State Pedagogical University. During the university studies, he met his wife, Annika Bornstrom, who is Swedish. Upon his graduation they relocated to Sweden. They have two young daughters.

After moving to Sweden, Sergei started to work at Mo Gard, www.mogard.se a leading private non-profit company providing social, educational and healthcare services to deaf and deafblind youngsters and adults throughout the country. Sergei started as a teacher, gradually advancing through Program Director and other positions. In 2005 he became the CEO where he has been responsible for managing a staff of 300 and extensive services for individuals who are deafblind. Along with improving the existing services, Sergei is successfully dedicated to expanding the reach of the programs nationally and internationally. Sergei represented Mo Gard on the Council of Deafblind International and has been active in their international efforts.

He has continued his education through Linköping University, Åhrens University in Stockholm and Strategic Perspectives of Non-Profit Management at Harvard Business School.

Sergei believes deeply in human ability to change the world through powerful action towards strong vision based on solid values. He says – "I am proud, humble and really excited to get the opportunity to contribute to this great venture and to carry on the impressive worldwide efforts from Mike and the team."

I know you will join me in welcoming Sergei and his family to the Perkins community.

Can you help?

Dear Sir,

I am the co-ordinator of the Guinean national organizations for deaf and blind people in republic of guinea.

Our goal is strengthening the capability to take charge of education of the deaf and blind. Our organization work is a non-profit and we are working for humanity in accordance with the International Convention on the Rights of the 'man.

We view your website for obtain some information about the mission of your foundation.

I want to talk about what I wish for the future for us deafblind people which demands we need to make upon society and upon ourselves, and what tools we have to help us reach our goal. For me, as for you, our goal is obvious. Our aim is a world where deafblind people live in the mainstream of society, equal to other citizens and with the same opportunities. A world where we have the same social, economic, cultural and political right as other citizens in our country.

A world where laws do not discriminate against us because we can not see and hear.

A world where we get the same chance of education and work as other people.

A world where deafblindness is accepted as a unique disability, and where we can get the service we need to live independently and with the same opportunities as other people. We must learn how to cooperate the ones with the others and other groups. We must learn the manners of the company so that we can make the good requests with the good authority. We write this message to you to ask for a help for the creation a hearth for most vulnerable of the deaf and blind. We need computers tools for the good starting of our activities. We are already in contact with the local authorities of the country to facilitate the administrative stapes. Instead of us to hide behind something, we ask you to make a humane proof and to help us to create this hearth for the deaf and blind. We have the same objectives, the reinforcement of the education system of the deaf and blind everywhere in the world.

Please help us to create this hearth and help us to obtain computers tools for the good starting of our activities.

Your faithfully,

Mr Jalloh Alpha Gassimou

The Coordinatoor of the Guinean organization for deaf and blind people

Bp:2652 Conaky-Guinea

Tel: +224 60 45 81 50
+224 67 45 81 50
+224 66 38 33 35
e-mail: khairyne2663@yahoo.fr

Seeking Poems by Deafblind People

Hello!

My name is John Lee Clark, and I am from the United States. I am working on an international anthology of poetry by deaf-blind people. This book includes poetry written in the past as well as by poets still living today.

If you know of anyone who writes poetry, please forward this message.

Also, if you know of any books of poetry published by deafblind poets or know of great poems published in periodicals or newsletters, please refer me to them.

Your quick response and action on this is much appreciated! Hoping to have good representation from all over the world in the anthology, I am

yours sincerely,

John Lee Clark

mailto:johnlee.clark@comcast.net]

Dear friends of DeafBlind International

I am writing you from Caracas, Venezuela. I am making a documentary about deafblind people in latinoamerica, I am focusing my work specially on the life of Miriam Torres.

I am really interested in your help in order to do a good job. I would love to show you my project so I can hear your comments and rethink some points. Also I would love to have a letter of support from your institution, if you are interested in that.

Sincerely yours,
Samuel Henriquez.

**Information Technology for Deafblind people –
the Colombian Government responds to need!**

Ximena Serpa reports:

The Colombian national association of the deafblind people, called SURCOE, had a change on the focus from a “rehabilitation service provider” to an advocacy one.

SURCOE participated in writing the law, 982, that recognized deafblind as unique disability in 2005 and has been working recently with the government to ensure that the law “does not stay in paper” and becomes a reality!

As a result of that, we presented a project to the communication ministry in which the human right of communication becomes a reality.

César Arévalo, from Sense International (Latin America) underlines that:

“In the last years the world had been thinking of technology to promote the autonomy of disabled people in all human development dimensions. Technology has generated new strategies for the social and work inclusion.

In the human rights approach, communication and information are a right that promotes other rights, for example if a deafblind person has the possibility of accessing information and communication, s/he can achieve the right of education or the right to work”.

Technologies in developing countries are still expensive for the “ordinary people” and if these are to be “adequate” for disabled people, it should be available for same the cost. Added to that, suitable technology is not easy to find.

That means the deafblind population is excluded from information accessibility, they cannot develop all their potentiality and they have to be at home as was the case of Pilar.

When Pilar was 22 she become totally blind and soon after she lost her hearing.

“I though I was the only one in this situation. I was isolated at home for twelve years. I did not know how the technology had improved and did not dare dream to be able to use it” she said.

Connected Senses

This situation changed almost one year ago when SURCOE started this project called “connected senses” supported by the Communication Ministry and launched an “Accessible IT room for deafblind people at the school for deaf and deafblind in Bogota”.

The project goal is to promote the social inclusion of deafblind people through access to information and communication, implementing the technology that is effective for deafblind individuals.

Today there are same IT rooms in three other cities in Colombia, paid for by the government and the project will cover 22 eventually across the country states.

“Now I feel accompanied, I have friends and I am learning” said Pilar when she comes to the IT room and learn Braille, how to use the computer, how to chat with others.

It is important that these initiatives are being developed in different regions for the education and work opportunities of deafblind people.

Adefav's Symposium discusses social inclusion

for deafblind people and multiple disabilities – “Social inclusion: interfaces between education, health and public policy”

Maria Aparecida Cormedi is founder and technical director of ADefAV based in Sao Paulo, Brazil. She is also a consultant of the Hilton Perkins Program for Latin America

The ADefAV/CRIFES – Resource Centre for inclusion in the Family, School and Society for people with multiple disabilities, deafblindness, visual impairment held the First International Symposium about Deafblindness and Multiple disabilities (SISDEM) in Sao Paulo, between the 9th and 11th of October.

Part of the motivation for this was to commemorate its 25 years of educational and therapeutic activities in support of deafblind and people with multiple disabilities. The symposium theme was “Social inclusion: interfaces between education, health and public policy.” It included meetings and roundtables with deafblind people, families, teachers, doctors, speech therapists, psychologists, educators and specialists from Brazil, Argentina, Uruguay, Colombia, Portugal, and the United States.

The event, aimed at professionals in the area of health, special education and public policy sector, also had the participation of families and persons with disabilities, who reported their experiences in workshops and described the strategies used to face the difficulties.

The SISDEM was designed to address the actions that guide the issue of inclusion in Brazil. It focused on inclusion enacted in a responsible manner, empowerment and family inclusion, training of professionals and the integration of the health system with the educational system. The expectation of the Director, Maria Aparecida Cormedi, “is that people leave the symposium with the willingness to change their attitudes towards prevention and intervention to enable responsible social inclusion to be fair and effective”.

Key themes

Research indicates that the number of premature children who are disabled is growing, and that the need of schools, medical care and educational expertise must grow as well. That is why early diagnosis is necessary. The

neurophysiologist, Veronika Bernstein, from Perkins School for the Blind gave a conference presentation and workshop about sensory disabilities, autistic behavior and Charge Syndrome.

Although the subject “inclusion” is not new, the symposium raised the flag about the need for public policies and the responsible implementation of inclusion. “There is not a decree that will include the child in school,” says the consultant of the Hilton Perkins Program Isabel Amaral. The Portuguese teacher criticizes what is currently taught in the classroom, claiming that it doesn’t serve people with disabilities. She argues for a philosophy that each school should be based on an interactive model, “which takes into account the needs, desires and interests of the student, but also highlights the needs and wishes of the family.” She believes that this model is about preparing children with multiple disabilities to be active members of society.

This requirements for real inclusion requires another look from the experts and for change to happen! These requirements range from the provision of equipment and materials to the development of a group of well-trained professionals, who have the same values, and the ability to network cooperatively in order to understand the strengths and weakness of each student. The curriculum needs to be aligned to each student and, most importantly, the ability to use what is learned at school in the community and at home must be developed. “It requires a responsible attitude and respect from the whole of society,” says Graciela Ferioli, regional representative of the Hilton Perkins Program for Latin America and the Caribbean.

The change in attitude regarding inclusive education, which overcomes the traditional model of intervention based on educational needs, was the consensus among the experts. Also a common point of agreement was the importance of the role of the family in supporting socialization and promoting inclusion and citizenship and the value of having the right to education and information in order to do this.

For the first time in Brazil, an event about deafblindness and multiple disabilities included lectures conducted by ophthalmologists specializing in low vision, ophthalmology paediatricians and neo-natologists who specialize in prematurity, multiple disabilities and functional assessment. This was done with the support from Brazilian Society for Low Vision.

Workshops

Roundtable events discussed the initiatives in Brazil to promote social inclusion for work for people with disabilities. The Program for Employability of Serasa and the Laramara Model (Brazilian Association for the Blind) both stand out for their hard work to qualify and prepare young people and adults with physical disabilities, visual and hearing to enter the employment market.

“This initiative pioneered by ADefAV seeks to give people with deafblindness the right to self expression, to assert their claims and rights, express their wishes and needs,” explains Cormedi.

These “expressions” are generally underestimated by society and, as a result, put the deafblind people in a subordinate relationship. This is the opinion of the founder and president of AGAPASM – Gaucho Association of Parents and Friends of Deafblind People and People with Multiple Disabilities, Alex Garcia. As a Deafblind person and an expert in special education in the last 11 years, he commented: “only when we become agents of the process will we participate on an equal footing in public policy.”

But there are also those people with disabilities, that express their desires, wishes and feelings using their body movements and their expression is not understandable to most people. For those people with multiple disabilities, the Symposium gave a voice to the family, who reported their feelings in the workshops. They talked about their efforts to get information to help better understand the problem and overcome prejudice to find inclusion and acceptance as a family. The families’ workshop was coordinated by Maria Veronika Cajal from Argentina.

Courses

Data from the Brazilian Ministry of Education – MEC, 2006, indicate that multiple disabilities are the third highest incidence in enrollment in regular schools. This requires school policies to attend the needs of communication, learning, mobility, adequacy of environments and equipment, and the provision of guide interpreters. Specialized in the training of professionals, the ADefAV/CRIFES gave mini-courses during the symposium focused on the issue of alternative communication as a pedagogical strategy.

Recognized by the qualifications of professionals working in the field of special education, ADefAV/CRIFES received from the Hilton Perkins Program (a partner since 1991) a special tribute for the work they have been performed throughout Latin America.

Thanks:

The I SISDEM was supported by of the Hilton Perkins Institute for Latin America, Acquaviva Promotions and Productions, UNIP University, Siemens of Brazil, FAPESP and Global Nexus – Strategies for Communication.

About ADefAV/CRIFES

The ADefAV/CRIFES is a philanthropic organization recognized in the third sector that develops work towards inclusion in the family, school and society of children, youth and adults with multiple disabilities and deafblindness. Founded in 1983 and based in Sao Paulo ADefAV/CRIFES is also recognized by consultancies and training courses, which develops educational and therapeutic communities for professionals with the technical support of the Hilton/Perkins for Latin America, the Perkins School for the Blind (USA).

www.edefav.org.br

News from WFDB

For those who do not know WFDB yet...

WFDB is a world wide representative organisation of persons with deafblindness. It has a constitution, a democratic structure and is registered in Denmark.

As the constitution says: WFDB is the legitimate voice of the deafblind population in the world (article 1.4)

The aim of WFDB is: "to improve the quality of life of deafblind people world wide, with the objective of achieving their equal rights and equal opportunities in all areas of society and to be a worldwide forum for the exchange of knowledge and experiences in the area of deafblindness and to increase international solidarity among deafblind people's organisations.

Since 1978 Helen Keller World Conferences for deafblind people have been organised with the help of the World Blind Union. Since the founding of WFDB in Auckland 2001, this tradition continued, combined with a WFDB General Assembly, under the full responsibility of WFDB.

As member of the International Disability Alliance, WFDB has been very much involved in the negotiations and now also in the implementation of this UN Convention, which is a very important new international law for persons with disabilities, family members and professionals in the near future to increase the quality of life, also for deafblind people. WFDB wants to have as many representatives with deafblindness as possible and also professionals working with them participating in this conference. If persons with deafblindness are not involved in the implementation of the Convention on a national level, they will be forgotten, being a very small minority.

The work of WFDB at the moment

WFDB is working together with organisation of the blind and the deaf, professionals and other partners to identify persons with deafblindness. One of the objectives of WFDB is to bring persons with deafblindness together on a local, national and of course an international level, bearing and mind that identification and assessment of deafblindness needs to be done in a professional way.

WFDB now has 57 countries represented. Asia and the Pacific region are scarcely represented and at the moment WFDB is much focussing on Africa, together with different partners in Africa.

Work in Africa

WFDB has organised three training courses for 10 African deafblind leaders from 10 African countries. The courses were organised in Kenya and Uganda with the participation of partners like: Shia, Hilton Perkins, CBM, secretariat of the African decade of persons with disabilities and Sense International. The purpose of the courses was capacity building and introduction to the CRPD.

WFDB is also planning a pilot project, together with partners to support deafblind students, studying under difficult circumstances at universities in Uganda. Their aim is to create a sustainable support system, including quality assessment of hearing and vision, provision of personal adapted hearing and vision aids, education in the use of hearing and vision aids, reliable and affordable battery supply and a system of maintenance and repair of technical aids.

Most persons with deafblindness in developing countries are living in the family, many very isolated. Much work needs to be initiated to create education and income generation. WFDB seeks as many cooperation partners as possible to realise progress. More work will be done in the Asia and Pacific region in the next years.

A UN International Deafblindness Day?

WFDB also has started to work on creating a UN International Day of Deafblindness on the birthday of Helen Keller. This is to promote awareness of deafblindness, worldwide, especially in those around 150 countries, where deafblindness is not recognised as a separate disability. In many countries the 27 June is celebrated as national deafblindness awareness day, and some countries even celebrate a week of disability awareness around this date.

This needs the involvement and support of many organisations and partners and of course the UN system, including the UN General Assembly.

Lex Grandia President WFDB

Details of our conference in Africa are on page 42.

Encouraging Developments in Latin America

ICEVI President Larry Campbell reports exciting progress in the “Education for All” campaign for children with visual impairment. Latin America is forging ahead!

Most Dbl members will now be aware of the “Global Campaign on Education for All Children with Visual Impairment” (EFA-VI) launched by the International Council for Education of People with Visual Impairment (ICEVI) in partnership with the World Blind Union (WBU) in 2006. For those who may not be aware of this global initiative to reach the estimated 4.4 children without access to education we invite you to learn more at our website www.icevi.org.

In this and future issues of your magazine ICEVI hopes to share more regional and country specific news about the EFA-VI global campaign in hopes that you and your organization will become more actively engaged in helping to assure that children and youth with deafblindness are part of the this initiative.

The Latin American region of ICEVI is off to a fast and impressive start in its efforts to reach the majority of children with visual impairment who are not today in school. EFA-VI national programs are already underway in the Dominican Republic and Paraguay. National plans have now been completed for four additional countries (Honduras, Ecuador, Nicaragua and Peru) that will be launched in 2009 with two more (probably Guatemala and Bolivia) to be added in 2010.

This progress is only possible because of the fact that the international community in our field has embraced the EFA-VI global campaign as a joint effort with a mutually agreed upon approach in which all partners feel ownership. This spirit of “community ownership” at both the regional and national levels was very apparent in a recent meeting convened by ICEVI and hosted by the Spanish National Organization of the Blind in Madrid. In addition to ICEVI and WBU’s regional body ULAC the meeting was attended by representatives of CBm, Hilton-Perkins and ONCE/FOAL.

Each of these organizations is International Partner Members of ICEVI with well-established technical assistance programs in the Latin American region.

However, by coming together around the EFA-VI regional campaign in Latin America, all partners feel that they will add value to their ongoing efforts and assure that they secure maximum benefit from the resources they are investing in the region. The group also sees future potential in conducting joint fund-raising approaches where the collective influence of the total group may enhance the chances of attracting major donors.

The group has formalized this new partnership with an EFA-VI Latin America Working Group chaired by Lucia Piccione, ICEVI regional chair. The Working Group will meet again in March, 2009 in Columbia within the context of a regional meeting being organized by ULAC with support from ONCE/FOAL. At this meeting we hope to be joined by our newest International Partner member the New York Institute for Special Education that has just a special interest in the Latin American region and has pledged US\$500,000 in support to the EFA-VI Global Campaign over a three year period beginning in 2009.

While the “climb” to reach educational equity for all children with visual impairment, including those with deafblindness, is surely a steep one; by working together as a community under the broad banner of the ICEVI-WBU Global Campaign we are demonstrating that we can and will achieve our goal. In your next issue we hope to share with you and update on the EFA-VI campaign in the Africa region.

Want better services for persons with deafblindness? ... Go into politics!

Lex Grandia brings us up to date with the progress of the UN Convention with good advice for activists and supporters alike

It's law!

Now the UN Convention on the Rights of Persons with Disabilities, CRPD, has come into force as an international law, it is time to look at how we can use this legal document to improve the lives of all persons with deafblindness.

As I write, 136 countries have signed the CRPD. That means that in those 136 countries there is a process going on, to change national, federal or local laws according to the CRPD. Many countries have chosen to change national laws before making the next step: ratification of the CRPD. 41 countries, however, have already ratified the CRPD, but still need to change their national laws.

There are many provisions in the CRPD that are very important for children and adults with deafblindness. We all know that persons with deafblind form a very small minority. If we are not present, with a strong voice, when and where the national laws will be changed, persons with deafblindness, their families and professionals working in the field will be forgotten and not be mentioned at all.

If you want to see the list of countries that have signed or ratified go to:

www.un.org/disabilities/default.asp?id=257

What is going on and where?

The first step being made in many countries is to translate the CRPD in their national languages. It is usual in the UN that every document is being translated in the 6 UN languages: Arabic, Chinese, English, French, Russian and Spanish. More translations have been produced afterwards. If you want to see more translations go to:

www.un.org/disabilities/default.asp?navid=12&pid=150

The next question is: who is working on changing the national laws and which stakeholders are involved?

That differs of course from country to country. It often starts on a ministerial level, but also parliamentarians can be involved. Organisations of persons with disabilities should also be involved from the beginning. It depends on how persons with disabilities are organised. In those countries, where there is a national umbrella organisation, it is quite easy to find out how the process is going on and where. There are also national human rights institutions in many countries. It is also possible to get information about process from there.

What do we need to fight for?

The CRPD covers almost all areas of life, but there are some areas, where we really have to be alert that persons with deafblindness are not forgotten and involved in the national laws. I will give here a very short overview:

persons with deafblindness are persons before the law, no matter their ways of communication

persons with deafblindness need support to make their own decisions and not guardianship

persons with deafblindness have the right to

- communicate in the way most appropriate to them
- to learn their own communication and to be educated in the way most appropriate to them
- to chose where and with whom they want to live
- to fully participate in family life and in the community,
- to have personal assistance, including guides and interpreters
- information and information technology, including education material should be accessible for persons with deafblindness

n Braille should be recognised as a script, sign languages as a language

n early identification, diagnosis and intervention should be done in a multi-disciplinary way

n education of professionals working with persons with deafblindness should be guaranteed

Make alliances

Only a few areas I have mentioned here are really deafblind specific. I have learned from my work during the negotiations around the CRPD, that it is absolutely necessary to make alliances with other disability fields.

For example: the legal aspects of being a person before the law and notion of supported decision-making are also a very important issues in the field of persons with intellectual disabilities or psychosocial disabilities. The same applies to the issue of where, and with whom, to live. Braille is of course also something concerning blind persons and sign languages belong to the deaf community.

Although we want to have deafblindness recognised as a unique disability, we need to find areas of common interest to make our voices stronger. Making alliances also helps us to make others in other disability fields understand the barriers that persons with deafblindness experience. That process of explaining these subtleties to each other creates a climate of mutual understanding and makes it easier to find our way in the political system – together. The slogan: “together we stand, divided we fall” is extremely important to get political messages through.

The International Disability Alliance, IDA CRPD Forum is supporting disability organisations and professionals on a national level with general documents on the implementation of CRPD.

If you want to read more, go to: www.internationaldisabilityalliance.org

Conference

Listen 2 Me 5, Czech Republic, Olomouc

It became a tradition that every two years families with deafblind children meet at different places in Europe. Each of those meetings – in sunny Italy, in flat Denmark, in scented Spain or in green and bagpipe sounding Scotland – brought together all of the participating families and their deafblind children to enjoy many new experiences and, most importantly, to form mutual friendships. We would like to proudly announce that the next international meeting of families with deafblind children “Listen 2 Me 5” will be held in Olomouc at the turn of July and August 2010.

The Czech Republic is located in the northern hemisphere approximately in the centre of the European continent. As for the land area, it is a quite a small country.

But as for its diversity and attractiveness of each region, the country is very rich and diverse. The country has its firm foundations in a rich and fruitful history.

The Czech natural environment is formed by an interesting merge of mountains, lakes and rivers, meadows and woods.

The magic of Czech culture is the Czech cuisine, rustic architecture and, for sure, Czech traditions. We believe that after your visit you will leave with many new ideas, information and experiences in the area of deaf-blindness. And in addition to that, you will leave with many feelings of enjoyment. You will experience traditional Czech meals, Czech folk traditions and the beauty of the Czech countryside and Olomouc surroundings.

The main organizer is ZÁBLESK – Czech Association of Parents and Friends of Deaf-Blind Children – in cooperation with EDBN, DBI and Hilton/Perkins.

We will bring more information in the next issues of the magazine.

On behalf of the organization committee:

Ivana Reckova and Dana Sterbova

Záblesk, Czech Republic

Deafblind International Awards

Bernadette Kappan

The plans for the European Deafblind Conference are moving along. 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 Italy. I hope you will take time to review the criteria for the awards and to submit names for consideration. Please submit your nominations using the process outlined. All nominations must be received by May 15, 2009.

Announcement

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 May 15, 2009.

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

Awards Committee

Attention: Bernadette M. Kappen

The New York Institute for Special Education

999 Pelham Parkway, Bronx, New York 10469

bkappen@nyise.org

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.

Dbl Lifetime Achievement Award Eligibility Requirements

The Lifetime Achievement Award will be made to an individual who has 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 Dbl 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:

News from the Secretary and Secretariat

Dbl Secretariat is awarded to Australia!

Senses Foundation based in Perth Western Australia was very pleased at the news of being awarded the Dbl Secretariat and officially took over the duties from 1st August 2008. I, Elvira Edwards took on the role as Secretary Dbl and Bronte Pyett as the Secretariat Manager Dbl.

Secretariat handover in New Delhi

On 9th and 10th July, the Australian team attended very successful meetings in New Delhi for the handover of the Secretariat with the team from India and key members of the Dbl Management Committee. We were so thrilled to be able to meet in New Delhi to make a smooth handover of the Dbl Secretariat. We are honoured to be taking over this role and look forward to a positive working relationship with Dbl.

Work in progress

Much time has been dedicated to reviewing documents and reports to get a sense of past and current activities. The membership database has also been extensively reviewed and changes to the Dbl website are underway to make it a more useful and interactive site for members.

Successful meetings in Germany

September saw the first of the Council & ManCom meetings organized by the new Secretariat. The meetings were held in Wurzburg, Germany and were generously hosted by Blindeninstitut. Our sincere gratitude goes to Blindeninstitut and in particular Eberhard Fuchs for his tireless assistance in the lead up to and during the meetings which was enormously appreciated and whose support of the Dbl Secretariat was invaluable. The meetings were very productive and the level of involvement in all activities was extremely pleasing. Dbl President, William Green expressed his appreciation of the many tasks people took on to progress the very valuable work of Dbl.

When we meet again

ManCom is planning to meet in Italy in February 2009 and Council again in Italy in September 2009 just before the 7th European Conference. Preparations for these meetings are underway and details will be released in the coming months for ManCom and Council members.

Stay in touch

The Dbl Secretariat is looking forward to leading a new and exciting chapter over the next four years. We welcome and encourage you to keep in regular contact to assist us to achieve the goals and objectives of Dbl. Accurate membership information is vital in keeping records up to date. We rely on members to inform us of any changes to contact details and membership status. Your assistance with this task would be greatly appreciated and you can contact the Secretariat on email at secretariat@deafblindinternational.org

Central to the work of Dbl is to foster the development of services for children and adults who are deafblind of all ages. Your contributions make it possible for Dbl to achieve these outcomes and we thank you for your continued support.

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 three tiers of Corporate Membership:

Large Corporates:

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

Small Corporates:

Annual Fees between £ 300 and £ 1,500

Mini Corporates

Annual Fees between £ 100 and £ 250

Corporate Members can be nominated to sit on the Council.

Deafblind International Individual Membership

I would like to join Dbl as an individual member

I would like to renew my Dbl individual membership

Member details

Membership No.

Title Surname

First name

Organisation

Job Title

Address (Line 1)

Address (Line 2)

Town/City State/County

Zip/Post Code Country

Telephone no. Fax no.

(Please include country and area codes)

E-mail address:

Are you:

a deafblind person a family member a professional

Does your organisation work primarily for/with:

blind people deaf people deafblind people

disabled people other (please specify)

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

Dbl Review (please check one box in each category)

A. I would prefer to receive Dbl Review in:

English

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

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

Membership Fee please tick where appropriate

I wish to pay an annual membership fee of £ 30

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

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

Corporate Membership

There are three tiers of Corporate Membership:

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

Small corporates Annual fees between £ 300 and £ 1,500

Mini corporates Annual fees between £ 100 and £ 250

We would like to join Dbl as a Large / Small / Mini

Corporate Member (please delete as appropriate)

We submit an annual fee of d

Corporate members are entitled to receive 25 / 10 / 5 copies of Dbl Review. We would like-_____ copies in n English

(delete as appropriate)

Member Details:

Organisation

Representative

Address (Line 1)

Address (Line 2)

Town/City State/County

Zip/Post Code Country

Tel:

(please include country & area codes)

Fax:

(please include country & area codes)

Email:

How to pay?

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

Payment method Bank Transfer Credit Card Cheque

A) Payment by Bank Transfer

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

Name of Bank: RABOBANK

Address of Bank: Sint-Michielsgestel, The Netherlands

Account Name: Instituut voor Doven: INZAKE DBI

Account Number: 11.29.09.825

Swift Address: RABONL2U

IBAN: NL31 RABO 0112 9098 25

Date of Bank Transfer:

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

B) Payment by Credit Card

Card type: n VISA n American Express n Mastercard

Card no:

Expiry date Name on card:

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

C) Payment by cheque

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

Please fax this whole page to (08) 9473 5499 or return to:

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