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Review



Charlotte creating one of her works of art

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

Dbl Review is published twice yearly, the two editions are dated January and July.

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 are welcome.

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A message from the President

Dear Friends and colleagues,
As I am writing I have been reflecting on the many challenges we all seem to be facing. It's very difficult with finance nowadays; grants and donations are getting harder to achieve. We are all needing to work twice as hard in some cases just to stand still and I know many organisations are cutting back.

Set in this rather dismal context it was wonderful to see over 400 delegates at the second joint Asian conference of ICEVI and Dbl in Ahmedabad India this past April. The conference was hosted by the Blind People's Association and Sense International India who did a fantastic job in welcoming delegates from over twenty two countries.

Dbl held its management committee meeting in Ahmedabad prior to the conference where amongst many things we are starting to prepare for the world conference in Romania in 2015. We also received updates from our networks which you can read more about in this Review.

William Green attended the European ICEVI conference in Istanbul on our behalf and of course we are looking forward to the Dbl Conference in Lille later in August. We will have our usual Management Committee and Board



meetings in France and Elvira and Bronte are preparing for our AGM.

I know the work of the WFDB continues and we wish them the best for their Conference and General Assembly in November in the Philippines. I was particularly interested to see that the European Blind Union (EBU) held its first Deafblind Women's Forum.

So despite my rather depressing opening, clearly our energy levels haven't dropped and we are continuing to do some amazing things. Our magazine, as ever, gives you so much more information and of course there is our website and facebook page where we can post your news.

Thanks to all our partners and members for keeping us up to date with all their news but we can always do with more!

Kindest regards to all

Gill Morbey
President Dbl

LAST COPY DATE FOR YOUR NEWS: 18 OCTOBER 2013

Editorial

Dear Friends,

My job as Editor has become more and more interesting with each new edition. This is a great vantage point from which to see the scope of what is happening around the world and then have the opportunity to communicate this information to our members. I know that the authors are pleased that their work is promoted through this magazine; I'm sure they would also be quite happy to have follow-up comments from the readers.

I begin my message by referring to two articles: *Living with Deafblindness – A Better Alternative* and *Napoleon's Code in Europe*. The former article is a collection of thoughts from a focus group of individuals who are deafblind from the Kalorama Foundation in the Netherlands as they relate to the tragedy of the Belgian twins who took their lives earlier this year. The latter article are observations from Neuropsychologist and Psychogerontologist Christine Aktouche about what she calls the tragedy of the serious loss of self-esteem that so many seniors are experiencing with the growing incidence of multi-sensory impairment. While there are stark differences between the articles based on the reporter's perspectives, the conclusions mesh together closely. The Kalorama folks suggest there is much that society can do to support them to lead safe and meaningful lives; while



Christine suggests that there are services and sensory aids available but seniors need to make greater use of them to regain their loss of self-esteem.

In this edition we present articles covering such wide ranging topics as educational forums in Brazil; openings of centres of excellence and special workshops; Ton Visser's tour of the deafblind service programs in India; William Green's visiting fellowship in Australia; a study of services for multi-disabled students in Cordoba State in Argentina and a detailed study from Denmark about psychosocial issues prevalent in many children with Usher Syndrome. There are articles from Sense International which focus on the important work they are doing to support the development of services in the seven countries in which they operate.

Take a look at the article from Smile-Japan which traces Shin's persistence during a recent Asia-Pacific consultation process to demonstrate that the slogan

(continued on page 74)

Contents

A message from the President	Page 2
Editorial and Contents	Page 3

Articles

Vice President message	Page 4
How we benefitted from membership	Page 5
ICEVI-DbI 2nd Joint Asian Conference	Page 6
Linguistic development in people with congenital deafblindness	Page 8
Living with deafblindness: A better alternative	Page 13
Sense International: Influencing global change and local lives	Page 18
Sense International: campaigning successes in Peru	Page 20
Sense International: Early Intervention in Romania: It's Official	Page 22
Passable Landscapes	Page 57
The Napoleon's code in Europe	Page 72
Using the UK system of vocational training to shape the workforce	Page 75

Country News and

Feature Articles	Pages 24-56
Argentina, Australia, Brazil, Canada, Ireland, India, Japan, Mexico, Netherlands, Romania, South Africa	

Network News	Pages 64-71
ADBN, Social- Haptic Communication, CHARGE Syndrome, EDbN, Tactile Communications, Proposal for new network	

Conferences and announcements

8th DbI European Conference	Page 16
10th Helen Keller World Conference and 4th WFDB General Assembly	Page 17
Cognitive Assessment of people with congenital deafblindness (Denmark)	Page 63
Speech to Braille interpreting using JAWS software	Page 77
Mary Guest has passed away	Page 78

DbI News and Membership

Secretariat News	Page 79
The countdown begins for the 16th World Conference	Page 80
DbI Board Membership 2011-2015	Pages 80-82
Become a DbI Member today!	Page 83
Corporate Membership Listings	Page 84

Vice Presidents' reports

Bernadette Kappen reports:



Sharing is such a large part of what Dbl members do. When we are asked what is special about Deafblind International we can all agree that sharing information with our colleagues is at the heart of Dbl. Sharing helps us grow and provide better programs and services for individuals who are deafblind. We look forward to getting together to get updates on our programs and to learn about new projects. This is a unique aspect of our organization.

This year Deafblind International has continued to share information through Dbl Review, network conferences, the website and the new e-news. In reflecting back on our history, the area of sharing information and knowledge has exploded. As the economic situations around the world continue to struggle, it will be important for us to find ways to continue sharing. The website is one way to exchange information and I encourage you to send information throughout the year. There are so many

wonderful stories and we can only put so many into the Dbl Review. We might think about developing a wiki where we can comment on a topic and assist each other. The opportunities we have with technology are endless and I think will help us expand our desire to share with our colleagues.

The Conference in Lille in August will bring us face to face and it will also be an opportunity to hear from you about other ways you might like to share information.

Bernadette

Carolyn Monaco reports:



The first six months of 2013 have seen Dbl produce our 51st Edition edition of the Dbl Review. Our 50th has since been translated into Spanish and French and both are now available on our website. The soliciting and distribution of field related information that is of international interest is encompassed in our vision, our purpose and identified in our 2012 to 2015 Strategic Plan. Sincere thanks to the team of people who write, submit, translate, edit, design, print, mail and post, enabling us as an organization to see this portion of our vision through

to fruition.

In April I attended the Management Committee Meetings and the 2nd Joint Asian Conference of ICEVI and Dbl, "Towards an Inclusive Tomorrow" in Ahmedabad India. As always, it was a pleasure to meet with our Management Team and once again work our way through agenda item discussions and decisions that impact the future of this organization. It was also a wonderful experience to participate in this conference and begin to develop a better understanding of services and programs available to people in this

region of the world, as well as to hear about some of the more inclusive opportunities that are being realized. Our hosts couldn't have been more welcoming and it was a real pleasure to be there.

We now turn our attention to the upcoming meetings and European Conference in Lille France at the end of August. Looking forward to seeing some of you there! For those unable to attend we will make every effort to share what we learn through upcoming editions of Review and the website. Have a great summer!

Carolyn

Deafblind International ...

How we benefited from membership

"In each edition of the Dbl Review going forward, we would like to highlight an individual, a group of individuals or an organization that would be willing to share how they benefitted from membership in Dbl. In this issue I would like to share one of the many ways that I personally and the organizations I am affiliated with have benefitted."

Carolyn Monaco – Dbl Vice President

The Canadian Deafblind Association's membership in Dbl dates back to the mid 1970's when John McInnes initially became involved in this organization and encouraged other organizations and individuals across the country to do the same.

Over the last 40 years all aspects of deafblindness in Canada have benefitted from their affiliations with Dbl. Individual members, staff working for corporate members as well as students in our Intervenor and Specialist Teacher of the Deafblind Programs have accessed valuable information from both the Dbl Review Magazine and the Website. Canadians have attended Dbl conferences and we hosted the International Conference in 2003 which provided significant opportunity for face to face networking with colleagues from around the world, an experience many Canadians remember fondly to this day.



Carolyn Monaco, Cathy Pascuttini, Cathy Proll and Sue Hall in 2008 outside 'TouchBase', Sense Scotland

In 2008 the Ontario Chapter of CDBA organized a four person study group tour. The team visited programs in Denmark, England, Norway and Scotland, all as a result of previous connections made through Dbl. We will

be forever grateful to our hosts for their time, effort and willingness to share their knowledge and show us their centres and programs.

The ultimate result of these visits was that our dream to build a Resource Centre was realized. Each program we visited and each person we talked to influenced the outcome of the final product in some way. I believe that it's important that we recognize that the catalyst for those initial connections came through our membership in Deafblind International.

More detailed information and photos of the CDBA Ontario Chapter Resource Centre can be found in this edition of the Dbl Review.



Carolyn Monaco, Cathy Pascuttini, Cathy Proll and Sue Hall, May 2013 outside the Resource Centre Inspired by Touch Base, Sense Scotland

ICEVI-DbI 2nd Joint Asian Conference

'Towards an Inclusive Tomorrow' April 5-7, 2013 – Ahmedabad India

The 2nd Joint Asian Conference of DeafBlind International (DbI) and International Council for Education of the Visually Impaired (ICEVI) was hosted by the Blind People's Association (BPA) and Sense International (India) in Ahmedabad, India, April 5-7, 2013. The conference, attended by some 413 participants from 22 countries, was considered an unprecedented success. The participants included officials from Governments in the region, international non-governmental organizations, professionals from universities, teachers, parents,



persons with disabilities, voluntary organisations, social workers and general education institutions.

The conference was opened by Mrs. Stuti Kacker, Secretary, Department of Disability Affairs, Ministry of Social Justice and Empowerment, Government of India. Mrs. Gillian Morbey, President, DbI and MNG Mani, CEO, ICEVI welcomed the participants on behalf of DbI and ICEVI, respectively. ICEVI

and DbI expressed gratitude to Dr. Bhushan Punani, Regional Chairperson, ICEVI West Asia Region and Mrs. Nandini Rawal, Treasurer, ICEVI, both representing the Blind People's Association and Akhil Paul, Director of Sense International (India) for jointly hosting the event in such a grand manner.

Using the theme 'Towards an Inclusive Tomorrow', the conference focused on education, technology and advocacy. The Scientific Committee chaired by Mrs. Vimal Thawani, (Chair, BPA-India), along with her members from India, Nepal and the Philippines, ensured that the program was tight, meaningful and did justice to the theme and focus areas. There were close to 130 speakers in the Plenary and Concurrent sessions occurring throughout the three day event.

On Opening Day, April 5, various dignitaries made very pertinent statements connected with the theme of the conference. Mrs. Stuti Kacker mentioned that "persons with disabilities should be treated as equal citizens who have a right to services". Mr. Pincha, the Chief Commissioner, Persons with Disabilities, New Delhi, himself a blind person, said: "that quality of services is more important than the mode of delivery of services".



Mr. Kevin Carey, President Royal National Institute of the Blind suggested that: "blind persons need to be given training in modern communication techniques and technologies. Shishna, a girl with deafblindness, said that she wanted to grow up as normal as possible and achieve all the dreams like any other person has. Dr. Jan van Dijk, an expert in deafblindness and multiple disabilities, demonstrated through a video that even a child with multiple disabilities can respond to love and be trained.

The afternoon included concurrent sessions ranging from Inclusive Education, to literacy for children with multiple disabilities, to self-advocacy, etc.

The evening featured children with multiple disabilities and visual impairment entertaining the audience with a cultural program. The program also included tribal dances, patriotic displays and



All photos credit: Dhuri Bharat

All photos credit: Dhuri Bharat



All photos credit: Dhuri Bharat

bollywood numbers.

The second day, April 06, began in the morning with presentations about inclusion of multi-disabled children from infancy to adulthood, early intervention, early childhood education, etc. Other presentations included: legislation as the means for transforming lives of persons with disabilities; the importance of advocacy, legislation and technology in empowerment.

In the afternoon, concurrent sessions dealt with transition, importance of play, networking, etc. There also was a unique rapid-fire session where 13 speakers were given 4-minutes to speak on a range of topics, including inclusive chess, role of parents, adaptive physical education, etc.

The participants were given the opportunity to visit the Ghandi Ashram before attending the Gala Dinner at the Cama Hotel. During

the Gala, the Sense Jagdish Patel Award for outstanding work in the field of deafblindness was conferred to the Helen Keller Institute (Mumbai) and Clark School (Chennai). These two institutions have trained over 500 teachers for the deafblind. Several special awards were also presented. Other individuals were congratulated for special contributions to people with disabilities.

The last day, April 7, featured a panel discussion on what makes inclusion work and one about finding common grounds for inclusive development. Dialogue took place discussing the role of the government and international NGO's in developing services through networks.

The final session was the Resolution Session. The Resolutions, called the Ahmedabad Declaration, were presented to

the Chief Guest Mrs. Sangita Singh, Principal Secretary, Primary Education, Government of Gujarat State.

The organizers thanked the Conference sponsors – CBM (Christian Blind Mission), National Trust, Perkins School for the Blind, Stichting Shared Vision and UKaid - for without which the Conference would not have been such a success.

Further details about the conference can be found on the webpage of the Blind People's Association (<http://www.bpaindia.org/Newsletter.htm>) and on the conference website (www.icevidbiasia.org) where a photo gallery is available along with the list of conference attendees and responses from some of the participants.

Note: Article is an abbreviated version from the BPA Newsletter.



All photos credit: Dhuri Bharat

¹ www.en.wikipedia.org

² Founder of Blind People's Association

³ www.cbmun.org.uk

⁴ www.thenationaltrust.in

⁵ www.perkins.org

⁶ Stichting Shared Vision is a Dutch Foundation based in Oegstgeest, Netherlands (www.sharedvision.nl)

⁷ www.fundforgos.org

Linguistic development in people with congenital deafblindness

Assessing potentials for learning during interaction

From the onset of birth the child interacts with the world around him. He begins to communicate through interpreting the people around him; verifying the suitability of his activities and behaviour. Through selecting those most effective communication strategies by imitating the successful interactions, he develops his communication gradually until it becomes a language.

People have a communicative behaviour which understands perfectly that those with whom there is an intention to communicate have similar abilities to receive stimuli and share with us the same mental representation of reality. When individuals do not have these equal possibilities to receive stimuli, because they have serious limitations in their sense of hearing and sight, they do not respond in the expected communicative manner and this causes a situation that blocks communication.

People who are born deafblind or become deafblind just after birth have great difficulty beginning the communication process. The fact of not knowing who is close by or what is happening around them results in a general lack of interest for interacting with people.



Pilar Gomez

Consequently their emotional expressions are not clearly understood by others around them. This is because these expressions are the result of their own personal tactile perception instead of being interpreted by their intervenor (also known as a Communicator Guide etc). If there is no intervention, the communication process will not begin, which interferes with language development.

In order to make the communication development process happen in people with congenital deafblindness, it is necessary to have competent interlocutors or intervenors.

These individuals are able to, through the observation of an action by the deafblind person within a specific context, interpret the action's meaning. The consequence is that the interlocutor can offer an easily understood and coherent response, according to what the deafblind person expects. The person with deafblindness will feel, because of this intervention, that his action has meaning and is shared by his interlocutor. This shared meaning will encourage the individual to use the same action in future situations when he wishes the same reaction. The success of his

action and corresponding response will encourage new communication interactions which will be repeated.

Building shared meanings is a key aspect in the process of communication development and this becomes especially difficult when one of the two participants in an interaction is a person with deafblindness. This is due to the fact that deafblind people's experience of perception is closely linked to **proximal** tactile stimuli, which makes it very different to the one held by the interlocutor who can see and hear and relies on **distal** stimuli.

The mental 'track' or representation from these two different perceptive experiences will obviously be very different for each person. For this reason, the symbolic elements used by interlocutors to express this experience will also be different.

This shared experience and the context in which the interaction is produced, requires a negotiation of meaning. Only an experienced interlocutor will be able to understand the actions of the person with congenital deafblindness. The interlocutor will be able to give the deafblind person an encouraging answer that will form the basis for further improvement of their communication.

From this previous discussion, we can make a number of statements:

- The process for persons with deafblindness developing communication and acquiring language happens the same way

as those seeing and hearing individuals. This occurs as the result of numerous social interaction experiences occurring in different situations.

- It is impossible for adequate development of communication and language acquisition to take place in the person with congenital deafblindness without intervention.
- The person with deafblindness needs 'special' expert interlocutors to provide this intervention. These interlocutors or intervenors are necessary to interpret situations to the deafblind person to satisfy their perceptual understanding. This process largely involves using tactile communication to interpret the actions and expressions that the person with deafblindness can understand.

Intervention with people with congenital deafblindness: The educational process.

A meaningful constructive educational learning process is key to the development of people with congenital deafblindness. In order to make this process happen, we need people to intervene with these individuals by interpreting the environment, acting as a model, helping to orient them in their particular situation and encouraging them to play an active role in their own learning.

The main difficulty that people with congenital

deafblindness have is being aware of what is happening around them. They need to learn both how they can be understood by others and how others can understand them. This difficult situation severely weakens their interest in interaction thus limiting their ability to communicate and acquire language. Intervention offers a way to overcome this difficulty.

Good cognition, demonstrated through awareness, perception, reasoning and judgement is a necessary requirement for adapting to ones' environment and key to communication and linguistic development.

The main goal of intervention for people with congenital deafblindness is to develop their cognitive potential to allow them to live fulfilling lives within a family context and society as a whole. It should be understood that critical to achieving this potential is the development of communication; acquiring language preferably in the person's mother tongue.

This goal can be achieved in four ways:

- **Developing a broader awareness of the world** (including people, animals, plants, the environment, various activities, etc)
- **Providing varied interaction situations** that facilitate the acquisition of learning.
- **Motivating the communication**

development process by offering coherent responses to each action, interpreting expressions, regardless if they are actions or not.

- **Promoting the development and acquisition of language** by offering a linguistic model that, adjusted to the deafblind person's perceptive system, will allow him to communicate in the society in which he lives.

1. Developing a broader awareness of the world

A human being has basically two ways of interacting and knowing his environment. One way involves the direct contact with environmental stimuli; the other involves interactions with others through shared experiences.

If one of two people who are interacting has more cognitive, communicative and linguistic competence than the other and guides the interaction with the objective of building learning, we say that this learning experience has been mediated.

People who are deafblind need to know the world around them through shared experiences gained through mediated learning.

People with congenital deafblindness lack appropriate sensory modalities seriously interfering with acquiring information and learning. Therefore these individuals require mediated learning through using intervenors to facilitate their understanding by interpreting the environment around them.

The success of this mediated learning is dependent on the intervenor being able to:

- Actively involve the person with deafblindness such to attract his interest.
- Help the person with deafblindness learn to react to unexpected events. This process should mean that the



intervenor needs to understand the meaning that the deafblind person gains from each experience.

- Achieve reciprocity in the interaction; that is to say, achieve a response from the person with deafblindness to each of the intervenors proposals, while at the same time the intervenor responds to each of the actions of the deafblind person.
- Make the learning successful and meaningful. For this the intervenor needs to make clear what he wants the person with deafblindness to learn.
- Ensure that the total experience is meaningful.

These experiences have to be well planned to help the person with deafblindness build his knowledge.

2. Providing varied interaction situations. The first level of intervention

It is not easy for intervenors to readily adapt their knowledge interactively with people who are deafblind. For them it is difficult to identify and immediately react

to responses or communications that the person with deafblindness presents. It may be difficult for the intervenor to recognize whether these interactions are functional and meaningful.

A non-recognition response from the intervenor to actions of people with deafblindness will quickly reduce the quality of the communication interaction, which will inevitably lead to negative and unwanted results.

It is essential therefore that the intervenor or interlocutor care about the quality of their interaction. They must adapt their interactive and communicative conduct to the response or behaviour of the person with deafblindness at every moment to ensure that the person always feels he is being attended to and understood.

One way of doing this is for the intervenor to imitate what the person who is deafblind is doing. The person who is deafblind might then be able to notice how his behaviour can affect his interlocutor's behaviour or response. We can get him to repeat the process and imitate at the same time when he feels



he is being imitated. This should create a pathway, taking similar turns, i.e. be imitated – imitate – be imitated (listen, answer, listen). This behaviour shows that the deafblind person has perceived, although in a different way, some meaning in his interlocutor's action. This introduces a synchrony in the interaction.

This regulation of interaction by both individuals (you do – I do – you do) is a prerequisite for the development of a good relationship of trust for the person who is deafblind. This should facilitate an enhanced contact with the world around them, thus optimizing the learning processes.

The main objective in this first level of intervention is ensuring that the person with deafblindness successfully participates in the interaction.

3. Motivating the communication development process- the second level of intervention

You might say there is successful communication when: a) a person offers a specific response

to another person's specific behaviour; b) a person's particular behaviour seems to imply a certain intentionality, anticipating an appropriate response, or c) there is a level of reciprocity of behaviour between two people, leading to the beginning of a dialogue.

Once the person with congenital deafblindness has discovered things and people around him which have attracted his interest, has realised he can be listened to and receive appropriate answers through interaction - he will try to communicate. However, he will only start communication when he feels accepted and trusts that his message will receive attention.

First, he will do this according to the mental trace that the perception of the stimuli has left with him. He will bodily express the thing he felt, where he felt it; then wait to be understood for the event to take place again. This moment represents a communicative interaction.

Offering an appropriate response to the beginning of a communication action is essential to ensuring that the communication starts and develops. This development of

communication will be reduced if we do not find a way of introducing a more elaborate process. In short, we need to develop a proper language which gives relevant information about everything that attracts the person's interest, such that it can be received, understood and imitated. This will allow him to become an active participant in this conversational dialogue.

This reflection makes us think about the most important and, at the same time, the most difficult question to which professionals must give an answer: **is it possible for people with congenital deafblindness to develop language, that is to say communicate at a linguistic level?**

From our own experience working with deafblind people, the answer is a definite YES. The degree of YES, however depends on a number of variables:

- the moment at which the intervention begins,
- the amount of interesting interactions that can be achieved
- the quality of these interactions, depending on how well communication adjustment has taken place and the competence of the intervenors and,
- Individual characteristics of the person with deafblindness. Whether the person has an associated deficit or not and understanding the nature of these deficits that require special consideration

The second intervention level must have the development of communication and shared meanings as a priority.

4. Promoting the development and acquisition of language – the third level of intervention

Through language one can share personal experiences and regulate the joint action that takes place in a subtle and cooperative way, categorising reality and making deductive inferences. Language is not only a system of relating to others; it is also used to communicate with oneself and organize thoughts, so that it also becomes a system that makes it possible to describe reality and to create thoughts that would otherwise be impossible to reach without this powerful means of representation.

It may be easy to question the possibility that people with congenital deafblindness, especially those without residual vision or hearing, could communicate at a linguistic level. But at the same time, it is important not to dismiss the possibility. Having said this, we should recognize that the lack of appropriate communication prevents the congenitally deafblind person from having relationships with other people, affecting their opportunity to fully grow as a total person.

Once again we say that to develop these communication skills, the deafblind person requires an intervenor or interlocutor to make contexts perceptively clear to them. The deafblind person needs to receive the language clearly, be able to understand and then imitate it. To achieve these results, the intervenor must be competent in many aspects. This includes competence in different communication methods (oral language, visual sign language,

tactile sign language, finger spelling); being competent in knowing how to interpret meanings, and understanding how a person who cannot see nor hear, perceives the world. This requires good training!

With respect to the use of tactile signs, tactile communication is always through sign language where the hands of the person with deafblindness must be on the hands of his interlocutor to be able to receive the messages. This process is reversed when the interlocutor expresses himself and/or expects to be listened to, i.e. the hands of the deafblind person are on the hands of the intervenor. The fingerspelling system may be introduced depending on the person's circumstances.

Oral language should accompany tactile sign language, whether or not the individual has residual hearing. The sign language should be considered an essential communicative support, until the person with congenital deafblindness becomes communicatively competent in that language.

The use of a signed language for the person with congenital deafblindness begins as a basic receptive communication accessible through touch. It should develop further at an expressive level through continuous imitation. The person will become ever so communicative.

A question is at what time, by what means and how much, should language be exposed to the person with congenital deafblindness to ensure that he is able to express himself linguistically?

Jerome Bruner proposes that one can only become fluent in a language when using it as a

primary means of communication. Is it necessary to have already acquired some language in order to be able to acquire language further as an observer. (Brunner 1990)

Paying attention to this idea, the exposure of the person with congenital deafblindness to language in our intervention model is developed as follows:

- It starts with the first contact with the person with deafblindness.
- It is a continuous process that takes place with every single interaction (whether the interaction is natural or caused) always searching for the most adequate form. We try to ensure that the exposure to language is as similar in duration to that which the person who can see and hear would have as is possible.
- It takes place with signed communication that is adapted to the age, level of functioning and perceptual abilities of the deafblind person.

It is essential to consider that there is a large discrepancy between the cognitive ability and the ability of linguistic expression in many people with congenital deafblindness. The task and responsibility for professionals is to find a way to reduce this discrepancy as much as possible.

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Living with deafblindness: a better alternative?

A focus group of deafblind people from Kalorama Foundation¹ in the Netherlands discuss adjusting to life with the loss of their primary senses

In January this year, deafblind twins from Belgium consciously chose to end their lives through euthanasia. The two 45 year old men were born deaf and became progressively blind. Their greatest fear was to live longer without the care of their elderly parents; they certainly didn't want to live on, totally dependent on their sense of touch. The parents and their brother wilfully supported the twins decision. There were mixed reactions in the international press. The Dutch press expressed general understanding of their position: if you are both deaf and blind, well yes, life might be too complex to be worth living. The other extreme could be found in the reactions of two American organisations, the National Association of the Deaf (NAD)², and the American Association of the Deaf-Blind (AADB)³, as can be seen in their statement about their *'grave concerns that the Belgian government has failed to provide meaningful support in life for its citizens, particularly those who are deaf and becoming blind.'*

On hearing the news, the consternation amongst deafblind clients and



Lieve Roets-Merken

their caregivers at the Kalorama Foundation in the Netherlands was extreme. While there was sympathy with the twins' decision to end their own lives, there was much concern for the loneliness and the powerlessness that spurred their decision. Both the Netherlands and neighbouring Belgium have similar and strict euthanasia legislation. Everyone in these countries understands that, to be actively helped with a self-chosen death, these twins must have been extremely convinced of their course of action. Even knowing this, it prompted one of our colleagues to say

what we were probably all feeling, *'Oh, if only I could have talked to them and got them in touch with other deafblind people, perhaps that would have shown them that there were other options.'* Every professional in the field of deafblindness had the same question: what role did the twins' professional caregivers play? As a professional caregiver, you must of course not overstate the importance of your own role. You're not responsible for other people's happiness, and you can't create a meaningful life for others. At the best, you can provide support. But, what is needed for this

¹ www.kalorama.nl

² www.nad.org

³ www.aadb.org



Kalorama Focus Group: Anneke, Ria, Gerard & Mieke

support, what should not be overlooked?

Increasingly, short-term rehabilitation programs are seen as being the most focused and effective form of support: the deaf person learns how to cope with progressive loss of vision and, vice versa, a blind person learns how to cope with progressive deafness. And, following this, the deafblind person is expected to live further alone, long and happy! Policy makers, health care insurers and caregivers not specialised in deafblind care and support seem satisfied with this form of care. Their consideration seems to be: 'surely if you can already cope with deafness, then it should only

be a matter of time before you learn to deal with your encroaching blindness? You start accepting changes in mobility; you learn to read with the many forms of visual aids, and you redesign your house to support you in this new phase! And, if you're blind and become progressively deaf, well, you adjust your forms of communication and then you're ready to take charge of your life under these new circumstances! And, in cases where you still have difficulties, what should you do? Well, perhaps a session with a primary care psychologist will help'. In these times of austerity and market forces, this appears to be an attractive and logical

approach.

So, we put this discussion to a focus group of six people, all of whom initially grew up with a single sensory impairment, then in their teens or later in life were confronted with a second sensory impairment. They all were aged between 32 and 56, either living alone or with partner. What follows is what they think and what they've experienced.

The group met once weekly at Kalorama. While they were also very shocked at the twins' choice of euthanasia, they recognized the despair that could lead to a decision like that. Will, who has recently joined this group, is deaf and becoming progressively blind. He's

convinced that, if it were entirely up to him, he would no longer bother getting out of bed! He feels that now, with the help of peers, he can more easily let go of the stress and the eternal worry about what's going to happen; what's my future going to be like. Deafblind peers help him to create awareness of deafblindness to others who are not similarly afflicted. They also help him see the humour in some situations; for example to develop the courage to, in the midst of a tour group, to ask 'could someone help me find the WC?'

When he was still young, **Gerard** saw how his deafblind uncle lived his life, and began, early on, to learn the skills he'd need later on in his own life. He understands that not everyone can follow this path. His social world is also limited, but the weekly group meetings help. However he still experiences situations where he'd just like to 'throw in the towel'. For example, at a party because of the noise he couldn't talk to anyone directly; he didn't know exactly where he was and where he had to go to; despite this, no one reacted to him. This case affected him so much that he simply went home, feeling powerless.

Annette is the only one of the group who was born deaf. She thinks that the other group members are more advantaged, as their speech is intelligible to others. She's always been dependent on translation by her caregivers; she can't 'read' speech, she can't read anything written. Most of her contacts are computer

“Increasingly, short-term rehabilitation programs are seen as being the most focused and effective form of support”

enabled. She enjoys chatting, discussing sports, cooking and other subjects with other deafblind peers.

Mieke calls the group 'my people'. She feels that if you have to do everything by yourself, this would mentally destroy you; 'then I simply don't think life would be worth living.' She urges family, friends and caregivers to undergo simulated deafblind experiences - let them experience the reality of being deafblind. She hopes that this will generate greater understanding, and that they'll be able to better manage their actions.

Ria notes that her blindness and her deafness are always there; they paralyse her. She finds group participation extremely exhausting; she really has to stay focused, and even then, has difficulties understanding. She feels safe in this group, as she can talk with others. Elsewhere, she always feels on edge.

Anneke agrees completely: contact with peers and specialised caregivers provide her a feeling of safety. She mentions the difficulties of communicating with her General Practitioner as an example: in his practice, quite a long way from the waiting room, he calls to his patients when it's their turn! If she then asks where he is, he answers, 'here.' She then responds: 'how can I know where you are?' Even after discussing this together, he

continues to do this!

Everyone familiar with deafblindness will recognize these shared experiences. Social participation and personal autonomy are especially endangered. These deafblind individuals illustrate that deafblindness requires from them a continuous, lifelong awareness and ability to adapt. Obstacles and problems can pop up everywhere and every time. Again and again, the deafblind person has to act or react. To survive these exhausting challenges, short term rehabilitation is necessary; but over the long term, regular contact and support from deafblind peers and specialised professionals - people who understand what we experience - is crucial.

Despite all this, it's a shame that society seems to understand that, due to the severity of living with deafblindness, people can choose to end their lives, whilst seemingly not being aware how much can be done by society to support deafblind individuals to lead safe and enjoyable lives.

Focusgroup Deafblindness Kalorama

Correspondant:
Lieve Roets-Merken,
Psychologist and Researcher
(email: L.Roets@kalorama.nl)
Kalorama Foundation
(www.kalorama.nl)



8th DbI European Conference

Identities and changes

Commonalities across deafblindness
Learning from each other

August
24-28, 2013
Lille - France



www.anpsa.fr
www.dbilille2013.eu
Contact :
assoanpsa@gmail.com



R.F.P.S.C
R seau Fran ais pour la surdit c t 



10th Helen Keller World Conference and the 4th WFDB General Assembly

The 10th Helen Keller World Conference and 4th WFDB General Assembly will be held at the Hotel Taal Vista¹, Tagaytay (60 km outside Manila), Philippines, November 6-11 2013, hosted by the Philippines National Council on Disability Affairs (NCDA)

Conference theme

Accessibility and inclusion for people with deafblindness in everyday life – CRPD for everyone everywhere.

Program

A future announcement will contain further information about the conference program.

Conference fees before August 01, 2013:

The conference fees for the whole conference will be:

- 300 Euros per person for deafblind persons, family members, interpreters/assistants from developing countries;
- 350 Euros per person for conference participants, interpreters/assistants from highly developed (industrial) countries.

After August 01, the registration fees will increase by 50 Euros per person.

The fee will include welcome reception (Nov 6), conference gala dinner (Nov 11), 5 days of lunches, coffee/tea breaks, mineral water and conference material.

Fees do not include transport to the conference, excursions, airport transfer, other dinners, visa, vaccination or other personal expenses.

The cost for day guest participation is 30 Euros, which includes lunch, coffee/tea breaks and water. Individual cost for welcome reception and gala dinner is 25 Euros.

For further details about registration for the conference, contact Christer Nilsson at hkwc13@telia.com or refer to the WFDB website: www.wfdb.org. Hotel booking can be done directly by contacting joan.abella@taalvistahotel.com



¹ <http://www.taalvistahotel.com>

Sense International: Influencing global change and local lives

Kate Mairs and Lucy Drescher

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lucy.drescher@sense.org.uk

Putting deafblindness and disability issues on the international agenda isn't easy. In developing countries where – understandably – there is an emphasis on ensuring that the most basic needs are met, it is even more challenging. But disabled people must not be overlooked, and campaigning to get their voices heard has never been more important. People living in poverty are already at a significant disadvantage, but add in a disability, and the challenges they face become all the more difficult.

In 2000 the United Nations (UN) agreed on the Millennium Development Goals (MDGs), which aim to tackle poverty around the world. But there was no mention of disability, despite 15 per cent of the global population being disabled. The MDGs expire in 2015 – and Sense International (SI), the

sister charity of Sense, along with a coalition of organisations are working to ensure that disability is included in the next set of targets.

Sense International was established in 1994 to support the development of services for deafblind people in some of the poorest parts of the world. Today the organisation works in seven countries – Bangladesh, India, Kenya, Peru, Romania, Tanzania and Uganda. Over the years SI has had a range of significant campaigning successes. For example we have:

- Worked with governments to provide specialist healthcare and education services for deafblind people.
- Raised awareness of deafblindness – from grassroots organisations to international bodies.
- Achieved legal recognition of deafblindness in four of the seven countries we work in.

This gives a snapshot of the work that has been done and there is much more to do.

Making the case

Zamir Dhale, who is deafblind and Senior Advocacy Officer for Sense International in India, recently presented at the Human Rights Council on deafblind /disability issues at the UN in Vienna. As well making a speech, Zamir also met with representatives from Australia, Turkey, Sweden and New Zealand. He was able to raise awareness of SI India's work

and the challenges faced by all deafblind people. He highlighted the lack of identification of deafblind people in developing countries, the complexity of their particular needs and the inaction by many governments in making adequate provision for their deafblind citizens.

From its UK head office, SI also works with the Department for International Development (DFID), which supports work undertaken by organisations like SI. DFID does not currently have any objectives around disability, nor does it require information about how disabled people are benefitting from the projects it funds.

In a bid to change this SI is lobbying DFID to get disability added to their agenda. An inquiry into disability and development has been promised for late 2013/early 2014. The findings could provide evidence that would put a greater focus on disability issues – drawing attention to the lack of support for this marginalised group of people in developing countries.

Campaigning at a national and local level

There is also a great deal of national and local advocacy work going on in both the UK and the countries where Sense International works.

- At a UK level, SI is meeting with MPs and Peers to persuade them that disability should be firmly on the new agenda. We have



linked up with a member of the UK's House of Lords, Lord Browne of Ladyton, who is an advocate on disability issues. Lord Browne recently gave a speech in the House of Lords which urged that disability should be included in the post-2015 MDGs. During this he referred to SI's work as an example of what can be done to improve people's livelihoods.

- In Romania, early intervention for deafblind/multi-sensory-impaired children has been embedded in the national education system. Romania now has the necessary framework to allow the development of the early intervention service for all sensory impaired newborns.
- In Kenya representatives, including parents of deafblind people, have met government officials to try to get amendments made into legislation, including initiatives to improve education for deafblind people.
- In Tanzania, country representative, Christopher Andendekisyie has made several appearances on national television to discuss disability issues and the work



of SI. This exposure has helped to put deafblindness and Sense International on the map – increasing awareness amongst the public and within government.

- India, Kenya, Tanzania and Uganda are also working to get important funding from GAVI, the global alliance on vaccination. In November 2011 GAVI made the decision to support the Rubella vaccine. Congenital Rubella syndrome affects approximately 20,000 people in East Africa and India. Country offices are lobbying their governments to put in applications to GAVI for funding

of this programme.

- SI Kenya is working with the Kenyan Institute of Research to establish a research project into the prevalence of Rubella. Without evidence it is unlikely that the government will put in an application – they require proof that a significant number of people are affected by Rubella, and that there is an understanding of how the vaccination programme could be implemented.
- In Latin America, at the end of 2012, Peru was one of the first countries to introduce legislation that falls in-line with the UN Convention of the Rights of Persons with Disabilities. The law ensures that people with disabilities:
 - are included in society
 - get an inclusive education
 - are appropriately represented in government
 - are able to access public transport.

For further information about campaigning and advocacy work in Peru, please see the article 'Campaigning successes in Peru.'



Sense International – campaigning successes in Peru

By Ricardo Zevallos Arévalo
Peru Director, Sense International
Email: rzevallos@senseintperu.org

“There is progress in the production and adoption of standards for deafblind people, but implementation remains a challenge.”

Deafblindness is a low incidence disability affecting an unknown number of Peruvians. Deafblindness has an impact on communication and access to information – leading to social isolation, segregation and exclusion. There are no statistical records of deafblindness in Peru which makes it difficult to set services for prevention, care and rehabilitation.

After a concerted effort by civil society, led by Sense International on May 2, 2010, the Law No. 29524 which recognises deafblindness as unique disability and makes provisions for

the care of people with deafblindness was passed. The law highlights the need to implement the interpretation guide service to meet the communication needs of deafblind people. Subsequently, on June 16, 2011, the regulations of the law by Supreme Decree No. 006-2011-MIMDES were approved. The regulation sets up an interpretation guide service in all government institutions. It states that the Ministry of Education approves requirements, profiles and the accreditation process for guide interpreters; that the National Council for the Integration of Persons with Disabilities (CONADIS) promotes awareness of the regulation within schools, audits the compliance

with the regulations and creates the Special Register of Guide Interpreters; that public institutions provide interpretation guide service from July 1, 2011 and private institutions from January 1, 2012.

The work done since the formal recognition of deafblindness was brought in has positively influenced the actions of government institutions, which have begun to bring about changes that allow the inclusion of the needs of deafblind people in plans, programmes, actions and activities.

The education sector has been working on an inclusive approach. Students with mild and moderate disabilities should be included in mainstream schools, and special schools should provide a quality educational service to students with severe disabilities and multiple disabilities. Deafblind students are considered students with severe disabilities. Progress has been made in preparing the guide interpreter profile and requirements and in the validation of alternative communication systems for deafblind people (already approved by the sector). There is a teacher training programme in deafblindness and a Guide for the Care of



Students with Deafblindness that has been developed by the education sector with technical support from Sense International.

The health sector has been implementing a national strategy of universal health insurance, offering various affiliate schemes to Peruvian citizens. The National Immunization Strategy has been in place for decades, with technical support from the Pan American Health Organization. Thanks to them, during the 2000s Rubella and Congenital Rubella syndrome (Rubella causes CRS) were eliminated; both one of the root causes of congenital deafblindness. However, there is not a good detection and certification system for deafblindness – health centres do not have a treatment protocol for patients with deafblindness and rehabilitation processes do not include them. With Sense International support technical documents were put together, including a Toolbox on Community-Based Rehabilitation and Toolbox on Physical Rehabilitation. There are Community-Based Rehabilitation programmes in Arequipa and Cuzco that can act as models of inspiration for the health sector.

The labour sector has been promoting various programmes that allow youth training and placement, promotion of corporate social responsibility, training and retraining of adults who are unemployed, or at risk, and temporary employment among members of marginalised and rural communities and

districts in the country. Most of the programmes have incorporated a participation quota of people with disabilities. The characteristics of deafblind people needs to be analysed separately, in order to be able to design and implement programmes tailored to their requirements and needs and to provide reasonable adjustments for their inclusion.

The women and vulnerable people sector, through CONADIS, has been developing various actions that allow the development of a statistical method of measuring the number of disabled people benefitting from programmes – this has been validated in the Tumbes region, to be available for future government interventions. The “I’m Able” Programme features people with disabilities as subjects, who are suitable for entry into the labour market; and there a Budget Programme that can focus its attention on the development of interventions in the areas of education, health and labour. In terms of support for deafblindness, thanks to initiatives provided by Sense International, a deafblind person was hired as a deafblindness specialist at CONADIS headquarters, and a group of young people with deafblindness took part in a bakery and pastry workshop in a government-funded Technical and Productive Education Centre - CETPRO. The new law on the rights of people with disabilities, passed in December 2012, creates new challenges



in terms of legal capacity, accessibility, educational care, community rehabilitation, non-contributory pension schemes, participation in social programmes etc. and how deafblindness can be included. Sense International has been invited to make comments and suggestions on plans for the regulations to go along with this new law.

The Peruvian Government has to understand the importance of the interpreter guide as a positive way to ensure the social inclusion of deafblind people in all areas of life.

The developments described are generating exciting, deep structural changes that create in-turn, new challenges. Gradually practices, policies and inclusive commitments of all relevant actors can allow people with deafblindness to have a future of participation and opportunities in Peru.

Early intervention in Romania – it's official!

In 2007, Sense International (Romania) – SI(R) along with several parents, family members, education specialists and medical professionals, identified the need to address a major problem – how to ensure early intervention services for babies (those up to three years old) born with visual and/or hearing impairments, so that by the time they reach kindergarten/school age, the chances for them to reach their full potential and become active members of society are dramatically improved. Although early identification and early intervention services are important in all types of disabilities, in the case of deafblindness, they are crucial.

This is why, six years ago, SI(R) took its first steps towards developing an early intervention project that would significantly improve the quality of life for deafblind and



Early intervention

multisensory impaired children in Romania. There are three major cities where SI(R) is currently supporting the early identification and provision of early intervention services for small multisensory impaired / deafblind babies: Bucharest (since 2007), Oradea (since 2008) and Timisoara (since 2009)

This project is implemented in partnership with local maternity units,

kindergartens, schools, school inspectorates and child protection departments. In practical terms, this programme means the hearing screening of almost 47,000 babies (in 5 maternity units), the visual testing of over 8,400 babies, the provision of early intervention services to almost 100 babies in 3 Early Intervention Support Centres, carried out by 3 multidisciplinary teams consisting of 12 medical specialists and 12 early intervention workers. It also means the active involvement of parents and family members and the development of a Curriculum for Early Intervention.

The results and achievements of this project and SI(R) lobby and advocacy efforts led to the approval of Law no. 3071/18.01.2013

Infant auditory screening



regarding the Ante-preschool Early Intervention Curriculum for Deafblind/Multisensory Impaired Children, which was published in the Official Gazette of Romania, part I no. 146, BIS on March 19, 2013.

This is an extraordinary achievement for Sense International (Romania). It is thanks to their efforts that Romania now has the necessary legal framework allowing the development of early intervention services for sensory impaired newborn babies.

The authors of this reference document in the field of deafblindness are: Gabriela Maria Jianu

-psychologist, Eva Magdalena Oprea - special education teacher and Carolina Ana Biro - psychologist. Special contributions were made by consultants: Andrea Hathazi - University lecturer, Ph.D., Mihaela Adriana Moldovan - special education teacher, Ph.D. and Stela Rodica Todea - physiotherapist.

This document is crucially important for the development of deafblind/ MSI children and it would not have been possible without the valuable support received from Mrs. Liana Mitran, General Inspector for Special Education within the Ministry of National Education.

Perhaps the last word is

best left to a mother, whose son, Mihai, benefitted from early intervention services in Timisoara:

"It is my strong belief that the early intervention programme changed Mihai's life. Unlike any other types of therapy he went through, early intervention happened smoothly, without him feeling any pressure to do anything, but rather to do everything by playing.

Early intervention works wonders. When you think there are so many other kids in need of early intervention who could benefit a lot from stimulation at an early age.... They need to be supported, the same way Mihai was."



Argentina Services Currently Available in the Province of Córdoba, Argentina

For People with Multiple Disabilities (2011)

Authors: Agüero Rita Valeria, Bartoletti María Soledad, Casanova Gisella Soledad, Cepeda Mariela Soledad, Chiaraviglio Maira Magalí, Lodeyro Pamela

Collaborator: Montenegro Gisel; Adviser: Ferioli Graciela

Interdisciplinary Researchers/Final work: Abascal Miriam, Bossio María Teresa, Pisano, Magdalena.

Introduction

Based on the experience we acquired during our internships and the reading material we had access to, it came to our attention that among people with disabilities in Córdoba Province, a number of them have multiple impairments. It was therefore important to carry out a study to identify these people, analyze their educational needs, and determine what kind of education they are receiving within the inclusive education guidelines.

Methods

This led us to our main research subject: What types of educational and social services provided by the institutions in the Province of Córdoba, Argentina are in contact with people with

multiple disabilities. Our objectives were to identify what services are offered by these institutions that work with people with multiple disabilities; learn about the main obstacles these organizations face, and find out about educational background of the professionals that work with this specific population. The collected information was analyzed through standard statistical methods.

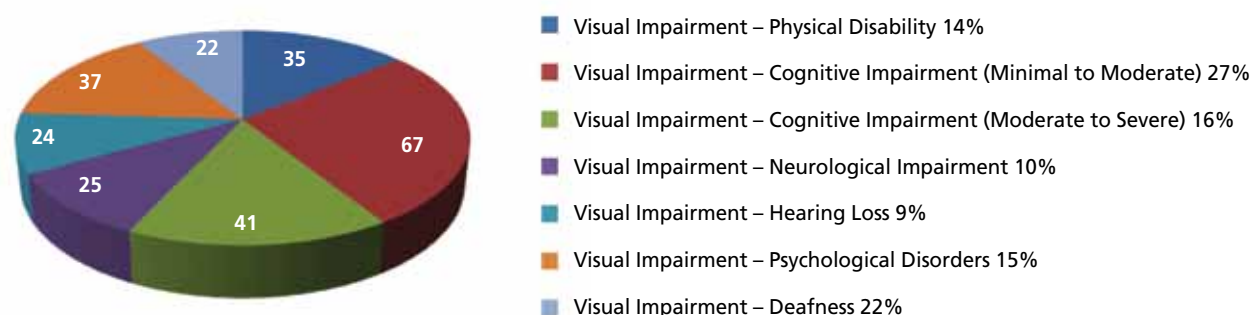
Results

Based on the survey results, 78% of the 128 institutions surveyed in the Province of Córdoba provide services to people with multiple disabilities. Regarding the financial support that these institutions receive, we can confirm that the government is actively involved in this service.

It was noted in the study that the services of the State Special Education Program is addressing the special service needs of children and youth aged 0 to 21 years of age with multiple disabilities who attend the school system. The program covers a range of services, from early identification and intervention through to high school levels.

Based on the representative sample of these individuals, 59% attend public funded schools, 25% are in schools which receive specialized educational support through a combination of government and private donors, while 16% attend totally privately funded schools. Only 1% of the surveyed institutions confirm having special residences for these individuals.

Fig 1: Disabilities associated with Visual Impairment



Types of Multiple Disabilities

The research examined the array of disabilities that were observed among those identified as multiply disabled. The individuals identified with multiple impairments were then organized into three broad groupings, based on what was considered as their primary impairment: Visual Impairment, Hearing Impairment and Motor Impairment. They were then further categorized as to their additional disability. Figures 1, 2 and 3 indicate the percentages of the various disabilities associated with the primary impairment - visual, hearing and motor impairment, respectively.

Without going into a detailed analysis for this paper, the authors wish to observe that the most noticeable multiple disability

inter-relationship was that identified in Figure 3. For those individuals identified in the Motor Impairment Group, the primary associated disability was cognitive impairment. The range of cognitive impairment ranged from 58% for those with minimal to moderate impairment to 34% with moderate to severe. While some degree of cognitive impairment was associated in the visual and hearing impaired groupings, none were observed to the same degree as with the motor impairment group.

Qualifications of Staff

The study examined the qualifications and specific training of the professional staff working with the different groups of individuals with multiple disabilities.

This examination

determined that while most of the professionals are very well educated through courses, seminars and conferences and even University, very few have received specialized training (i.e. post graduate education) in multiple disabilities.

Figure 4 (see next page), summarizes the academic background of the professionals working with this disabled population. Training levels ranged from: 55% having 'related' educational background (i.e. training in special education), 25% 'somehow related' background, (i.e. practical experience, courses, seminars, conferences, self-study), 13% 'specifically related' (i.e. post graduate education in multiple disabilities), while 7% did not have any related training at all.

This low (13%) overall proportion of staff

Fig 2: Disabilities associated with Hearing Impairment

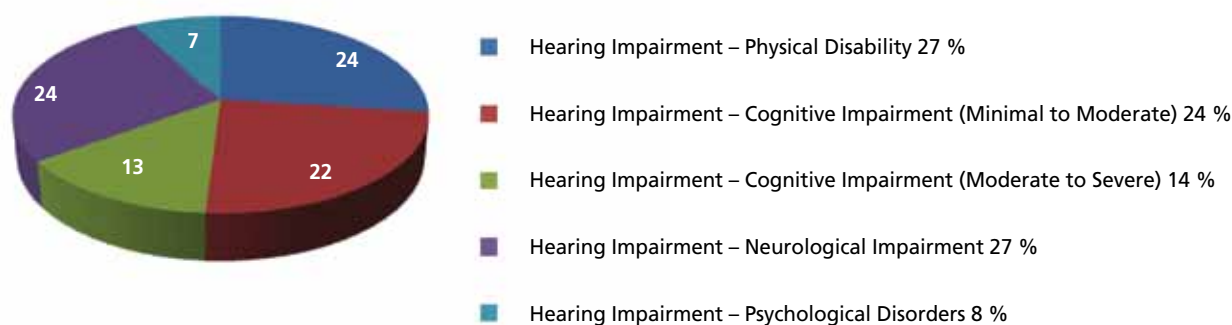


Fig 3: Disabilities associated with Motor Disabilities



Argentina continued



Authors from left to right: Agüero, Rita Valeria, Lodeyro, Pamela; Chiaraviglio, Maira Magalí; Bartoletti, María Soledad; Casanova Gisella Soledad. Missing from photo: Cepeda Mariela Soledad

having the appropriate qualifications to work with this population is concerning. While some practical experience combined with various short courses is important for staff, it does not replace the importance of staff possessing the strong theoretical knowledge which is usually gained through specialized education in the field of multiple disabilities.

When developing action plans and priorities to meet the needs of persons with multiple disabilities and their families, it is essential that professionals have the appropriate knowledge to develop these programs.

Conclusion

This study was undertaken to describe the current level of

services available for persons with multiple disabilities in Cordoba Province. Part of the study also included: describing general makeup of that population as well as investigating the qualifications of the professionals and care givers who work with this population.

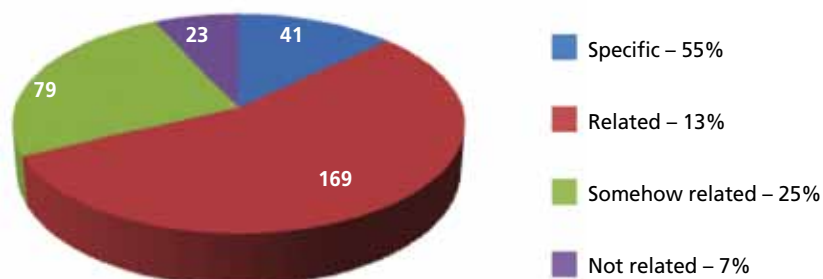
A better understanding of the complexity of this growing population will assist in determining the type of services that this population requires. Furthermore, the results will also permit the development of action plans and priorities to further the development of better services for these individuals.

One immediate observation from the study

was the determination that there are an inadequate number of professionals available with appropriate academic qualifications to work with these individuals with multiple disabilities. It is recommended that additional professional training programs, such as specialized courses, postgraduate studies programs, seminars, etc. be made available to improve the knowledge of all staff working with individuals with these multiple disabilities.

For more information about this study, contact Mrs Claudia Amusatogui, Director of Instituto Cabred
Email: dirección@cabred.edu.ar

Fig 4: Specificity of the academic background of professionals who work with people with multiple disabilities



Australia



Jeraldine Milroy (Australian Deafblind Council– www.deafblind.org.au) reports:

The Australian Deafblind Council is experiencing a period of evolution as Disability Rights and Policy in Australia start to blossom. In keeping with international standards and in recognition that Deafblindness is not the addition of two discrete disabilities, we have changed our acronym from ADBC to ADbC to reflect the Australian Deafblind Council rather than the Australian DeafBlind Council.

Alisa Wills (former Administration Officer) has moved from the ADbC into other areas of the disability sector where she continues to 'shine the torch of advocacy'. I have since taken on Alisa's role with the ADbC, my name is Jeraldine or "Jeree". My background is a Physiologist with a research interest in the perception of haptic communication.

Celestine Hare has retired as the CEO of Able Australia and Secretariat of the ADbC. With grace and strength Celestine shaped the Deafblind Association into Able Australia, creating a strong foundation to support Australians who are Deafblind. Able Australia is now has the honour of being led by Scott Sheppard,

well-known respected in the disability sector. He was recently awarded the Disability Professionals Victoria Fellowship.

While Dr Mike Steer has retired from his position as a professional committee member of the ADbC (and a previous organizer of this report), his contribution and dedication to raising awareness of Deafblindness continues to inspire.

The ADbC has been involved in writing submissions on Disability Employment, Draft Rules for the National Disability Insurance Scheme and a submission to the National Accreditation Authority for Translators and Interpreters (NAATI) recommending specific accreditation and training for Deafblind Interpreters. Full versions of these submissions can be viewed at www.deafblind.org.au/reports.asp

Australian National Deafblind Conference Sydney 2014

The Australian National Deafblind Conference convened by Forsight Australia has been postponed until 6th-8th June 2014.

For conference updates, please refer to Forsight Australia's website: www.forsightfoundation.org.au/conference/conference.html

Convention on the Rights of Persons with Disability

In 2013 the UN Committee on the Rights of Persons with Disabilities began dialogue with Australia in regard to its compliance with Convention on the Rights of Persons with Disability (CRPD) obligations. In April two Australian representatives from the Shadow Report Project Group went to Geneva to attend the ninth session of the UN committee to lobby for key recommendations contained in the Shadow Report. During the ninth session, the UN Committee developed a list of issues emerging from Australia's baseline

“With grace and strength

Celestine shaped the Deafblind Association into Able Australia, creating a strong foundation to support Australians who are Deafblind”

Australia continued

report. Australia will appear at the tenth session of the committee in September. While 2013 is the year for Australia's first hearing at the UN on the CRPD, it will not be long before Australia is due to do its second report. The shadow report as well as the list of issues that the UN Committee has asked Australia to respond to can be found at disabilityrightsnow.org.au

Visit by William Green

We were delighted to have the opportunity to have William Green, the immediate Past President of Deafblind International visit us while on his visting fellowship with Senses. He ventured to Victoria to attend 13th National Deafblind Camp, and visited Able Australia for a couple of days where he conducted a very dynamic workshop.



Deafblind Victorians meet Prime Minister Julia Gillard

Deafblind Victorians, formerly known as Deaf Blind Advocacy Group Committee, met personally with Julia Gillard Prime Minister of Australia and Jenny Macklin MP Minister for Families, Community Services and Indigenous Affairs and Minister for Disability Reform at the Community Cabinet meeting held at Norwood Secondary College on Wednesday, 17th April 2013.

It was an exciting day for the Deafblind Victorians (Trudy Ryall, Heather Lawson and Michelle Stephens) who met personally, for half an hour, with Julia Gillard and Jenny Macklin at a 40th Community Cabinet Meeting in Melbourne. The three ladies made very passionate presentations about their personal conditions, while stressing the need for ongoing support and services

for people with disabilities like themselves. To access the text of their wonderful presentations, contact Jeraldine Milroy at: info@deafblind.org.au.

Heather Lawson raised at the forum the issue of closing Auslan courses and the reduction of trained interpreters for Deafblind community. They all talked about the barriers the Deafblind community face today and self-advocacy for the Deafblind community. Trudy Ryall presented to them a DVD that was made with the Self Advocacy Resource Unit (SARU), Jodee Mundy and the Deafblind Victorians - a reflection on our lives and what it is like to be Deafblind.

Julia Gillard and Jenny Macklin received a Deafblind t-shirt each and were encouraged to practice their finger spelling printed on the back of the t-shirt.

Photo courtesy of Jodee Mundy Collaborations



PM Julia Gillard (in red) interacting during the Melbourne meeting.

William Green visits Senses Foundation in Western Australia

Australia
continued

Senses Foundation was delighted to host William Green, immediate past President of Dbl, as a Visiting Fellow for the three months from February to May 2013.

William's many years of experience working internationally in the field of deafblindness, most recently as Senior Consultant with Lega del Filo d'Oro in Osimo, Italy, an organisation with over 50 years' experience in the provision of services and research in deafblindness, was welcomed. A busy schedule of master classes, workshops, meetings and client consultations was organised.

William's trip was also timely, enabling him to contribute to a review of Senses Foundation's Deafblind Services, assisting with long-term planning around staff roles, training needs and the delivery of services.

William was able to offer advice and guidance as he met with management and staff, Senses Board and clients throughout all of Senses Foundation's services.

Meeting Linda

Linda, who is deafblind, comes into the office fortnightly as a volunteer for Senses and she met William on a couple of occasions. Linda shares her "William experience":

"I met William Green at Senses briefly. I also attended a talk he gave at Senses about Ushers Syndrome which I really enjoyed and learned a lot from.

William is a very dynamic, charismatic person and one feels one has known him forever. What struck me most is the way he engages with disabled people and doesn't shut them out or put them down but speaks to them on their level.

He has been the President of Deafblind International and has travelled all over the world empowering and helping deafblind people.

He has a great sense of humour and takes what deafblind people say seriously. He is not dismissive of our opinions or views.

His views on early intervention were exciting and the fact he wanted to involve deafblind people in having a voice was very inspiring.

Finally I found William to be a person who gets things done rather than remaining complacent and passive in the background."

Advocating for Senses

William lived up to his reputation as an advocate for people who are deafblind when he met with the Director General of the Disability Services Commission, the Western Australian government's funding body for services for people with disability. William highlighted the need for continued support through their funding of services to support the needs of people who are deafblind. William also met with officers from other funders of charitable organisations like Senses Foundation where he encouraged them to consider the needs of people who are deafblind.



Australia continued

The weekends were often not a time for putting his feet up!

The Usher Support Group invited William to join them on one of their events in March. The group met on the Swan River foreshore and found an idyllic shaded area with protection against the hot sun. Members of the group participated in water sport activities with William choosing to observe from the speed boat! A relaxing afternoon with a picnic lunch followed.

Staff training

In addition to William joining staff team meetings from the various departments throughout Senses, William attended a number of more formal training sessions throughout the month of March. One of the training sessions was opened up to a wider external audience and staff from the Association for the Blind WA, the School of

Special Educational Needs and audiology services welcomed the opportunity to attend.

The National Disability Services, the organisation in Australia which supports disability service providers, hosted a well-received sector wide seminar during which William shared his expertise with others in the disability sector.

March was also a busy month for travel

William joined a number of Senses staff and clients attending the Deafblind Camp 2013 organised by Able Australia at the Phillip Island Adventure Resort on the south coast of Victoria.

The weekend provided an opportunity for 39 people who are deafblind to get together for a weekend of socializing and fun. As a VIP, William was given the responsibility for judging the Mexican themed fancy dress competition!

Rural and Remote trip to the Kimberley Region of Western Australia

Senses Foundation staff regularly travel to rural and remote parts of Western Australia meeting with and delivering training to increase the knowledge and skills of those working with people who are deafblind.

As part of his trip, William Green accompanied Angela Wills, Senses Foundation's Coordinator of Deafblind Services and travelled to the Kimberley, the northern most region of Western Australia.

Workshops were held in Kununurra, which is over 3,000 kilometres from Perth flying via Broome. In Broome, the largest city in the Kimberley, clients, families, and a range of professionals including a student doctor, therapists, teachers and support workers attended workshops to learn about deafblindness and people who are deafblind, their needs and how to support them more effectively.

And - of course, a trip to Australia is not complete without meeting kangaroos!

Many thanks to William

All at Senses Foundation are delighted to have hosted William as a Visiting Fellow and are busy planning to take advantage of his next sabbatical!

Angela Wills (angela.wills@senses.asn.au)
Coordinator, Deafblind Services
Senses Foundation
(www.senses.asn.au)

Kimberley
Regional
Education
Office



Grupo Brasil announces the dates and location of the 5th International Forum

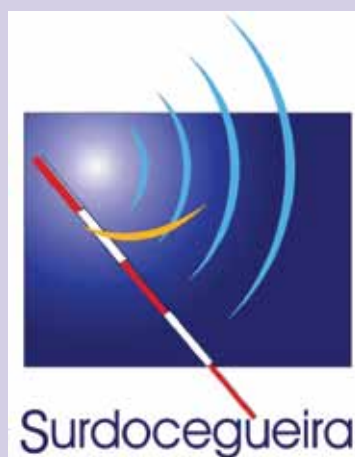
Brazil

on Deafblindness and Multiple Sensory Disabilities and associated meetings for 2013

Grupo Brasil, the National Network supporting people with deafblindness and multiple sensory disabilities in Brazil, is announcing its 5th International Forum on Deafblindness and Multiple Sensory Disabilities, at the Universidade Federal de São Carlos (UFSCar), November 21-23, 2013. Grupo Brasil is a partnership of Ahimsa (Educational Association for Multiple Disability), Abrasc (Brazilian Association of the Deafblind) and Abrapascem (Brazilian Association of Parents and Friends of People with Deafblindness and Multiple Sensory Disabilities).

Since 2004, Grupo Brasil has been sponsoring these forums which are designed to foster the development of public policies and implementation of appropriate services on behalf of families and people with deafblindness and multiple sensory disabilities. This event received the official designated ISSN registration number 1982-2669 beginning with its 2nd Forum in 2007.

The theme of the 5th International forum this year is: Holding Hands: Assistive Technology, Health and Education for the Inclusion of People with Deafblindness and People with Multiple Disabilities.



Coinciding with the forum will take place the VII National Meeting of Families and Professionals specializing in deafblindness and the VIII National Meeting of Deafblind People.

Incidentally, the dates of this event will occur during the Brazilian National Week for Deafblindness and the Municipal and State Day of the Person with Deafblindness.

The main objectives of the Forum are:

- Disseminate information on Deafblindness and Multiple Sensory Disability
- Present research being carried out in different states of Brazil and in other countries
- Promote the meeting of families for empowerment and to further organize the actions of the existing groups (Abrapascem)
- Promote the meeting

of deafblind people to empower the Brazilian Association of the Deafblind (Abrasc)

- Establish a partnership with a University to foster research and studies in the field
- Exchange experiences among established services around Brazil
- Exchange experiences with participant countries.

This International Forum and other associated organizational meetings are held every two years, usually in a different city in an attempt to reach all the states of this large country with its five distinct regions. We try to have the event with the support of an accredited University which brings more credibility to the Forum.

As an international event, international researchers are invited to present their studies and new accomplishments. This creates more opportunities for families, professionals and people with deafblindness and multiple sensory disability to meet and exchange experiences, strengthen their bonds and establish more partnerships.



Brazil
continued

1st Regional Forum on Deafblindness and Multiple Sensory Disabilities

Educational Perspectives in State Schools

Shirley Rodrigues Maia reports on a Regional Forum organized by Ahimsa (Educational Association for Multiple Disability) in the latter half of 2012 to assist the State Secretary of Education in the State of São Paulo to deal with the subject of deafblindness and multi-sensory disabilities in this large populated region of Brazil.

State of São Paulo. This was indeed a huge logistical task.

These meetings were intended to disseminate information about the disability. They were also meant to help the authorities properly identify the students (with sensory disabilities) that were already in schools but not receiving proper education for their disability due to the lack of knowledge about their condition and

2012. Shirley Rodrigues Maia, president of Grupo Brasil and educational director of Ahimsa, coordinated these information meetings, assisted by other professionals from Ahimsa. Claudia Sofia, representing Abrasc (Brazilian Association of the Deafblind), spoke about the needs of persons with deafblindness at all of the meetings.

As a result of the knowledge gained from attending these meetings, the schools were now able to identify their known disabled students as being multiple sensory disabled. Some 133 students were now identified as having multiple disabilities and 45 students identified as congenitally deafblind.

Based on this discovery, the State recognized that their staff needed additional training as well as the need to hire and train special intervenors to work with these students in the classroom. The current policy is that students identified as having acquired deafblindness have the right to have a guide-interpreter at school. Guide-interpreters are properly certified in the Ministry of Education of Brazil with a clear job description and receive



Claudia Sofia
Indalécio Pereira
(left); Shirley
Rodrigues
Maia (right)

This Regional Forum was organized through a series of meetings at eleven locations throughout the State. These meeting locations were selected to represent the 94 Departments of Education that are responsible for education in the 655 municipalities within the

appropriate educational needs.

Over 4000 individuals, including regular classroom teachers, special education teachers, educational directors, University teachers, graduate students etc., attended these sessions from August through November

“Ahimsa is working on this issue to ensure that intervenors are properly certified and paid accordingly for this career throughout the State of São Paulo”

Brazil continued



Secretary of Education of the State of São Paulo: Mr Herman Jacobus Cornelis Voorwald introducing a Regional Forum meeting

appropriate salary according to this classification. This situation does not currently exist for the intervenors who work with individuals with congenital deafblindness and those with multiple sensory disabilities. Ahimsa is working on this issue to ensure that intervenors are properly certified and paid accordingly for this career throughout the State of São Paulo.

There are a huge number of people with disabilities in Brazil. Enacting the policy

of inclusion is perhaps the only way to ensure they have the opportunity to interact with their peers and to guarantee their right to a formal education to prepare them for a better future. We must guarantee that these students receive appropriate services to meet their communication and educational specific needs. We do this by disseminating information, training professionals and helping to empower families. This is possible when we

work together with the government, universities and families focusing on actions like this one described in this paper.

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Canada

Canada's First Resource Centre for Congenital Deafblind Individuals opens in Paris, Ontario

The Canadian Deafblind Association Ontario Chapter (CDBA Ontario) recently achieved a big milestone with the opening of its Resource Centre in Paris, Ontario that is fully designed for people who are deafblind.

The new 13,380 square foot (1243 m²) Resource Centre provides CDBA Ontario with the ability to provide new programs and services for people who are deafblind across the province of Ontario in areas such as volunteer opportunities, music programs, sensory experiences, respite, social and recreational activities, art programs, and much more.

CDBA Ontario is very proud

of what's in this Resource Centre. The organization consulted with individuals who are deafblind, families, members and other community stakeholders to determine the contents. It took the collaboration of countless minds to create this uniquely accessible Centre and the organization is eternally grateful to everyone who contributed to the creation of this innovative Resource Centre.

Contained within the walls are: a two bedroom respite apartment, Snoezelen room, music room, boardroom, offices, tuck shop, communication lab stocked with accessible communication technology,



multi-purpose room, training classroom and a café. The café will provide volunteer and employment opportunities for individuals who are deafblind.

The CDBA Ontario Resource Centre is the first in the province that is uniquely designed to meet the accessibility needs of individuals who

Below: The resource Centre; top right: the music room; below right: the Snoezelen room





Executive Director Cathy Proll addressing the Centre Opening

are deafblind. It includes features such as ceiling lifts, an adult attendant area, fire alarms with strobe lighting, countertops designed for wheelchair access, Brailled and high contrast signs, as well as lots of natural light and specialized lighting. The halls of the Resource Centre are lined with uniquely textured railings. These railings provide visitors with tactile information that indicates which section of the building they are in. Considerations also went in to the colours used for the walls, kitchen countertops and floors and were carefully selected to highlight transitions or to communicate other important information.

The celebration of the Resource Centre opening began this spring with a special open house for individuals who are deafblind. Concrete cues were developed for specific areas in the Resource Centre. Over the course of three days, there were activities like introductions to the Snoezelen Room and

Music Room, Brailled board games, video games, and cooking classes as well as spa treatments that preceded a dance.

Old friendships were renewed and new friendships blossomed. These three days were filled with a lot of joy and tears of happiness as the new Resource Centre was brought to life! In total, approximately 50 individuals who are deafblind attended the events, some of whom came from places in Ontario as far as 350 to 800 kilometres away!

A few weeks later, On May 15, 2013, CDBA Ontario had its official grand opening for the public. Many families, staff, and friends came to experience the Resource Centre during an open house. CDBA Ontario was also warmly welcomed that day by many people from the local community who came to greet the organization. CDBA could not have asked for a more welcoming community to join and the organization is grateful for the heart-warming welcome received from everyone in

the town of Paris.

The day was capped off with a special gala dinner that was hosted by a local television personality with dignitaries on hand from municipal, provincial and federal governments as well as the board of directors, selected staff, and key supporters. It was a great opportunity to reflect and celebrate how far CDBA Ontario has come in 20 short years.

The vision for Resource Centre goes all the way back to the early days of the organization, when CDBA Ontario board members including Chuck Bulmer and Stan Munroe dared to dream big about a centre designed for individuals who are deafblind.

The dream was kept alive through the years by the board of directors. In 2008 a CDBA Ontario study group consisting of Carolyn Monaco, Susan Hall, Cathy Pascuttini and Cathy Proll had the opportunity to visit Scotland, England, Norway, Denmark and Vancouver. CDBA Ontario has been working hard ever since to make the concept of our very own Resource Centre a reality and are proud to say that this dream has come true!

Canadian Deafblind Association Ontario Chapter's envisions a future where "all people who are deafblind will live rich meaningful lives". The Resource Centre is an important step to realizing this vision.

Devin Shyminsky
Email: dshyminsky@cdbaontario.com
www.cdbaontario.com

**Canada
continued**

Canada
continued

Intervenors at Deafblind Ontario Services are now Certified!

Founded in 1989, DeafBlind Ontario Services is the largest not-for-profit organization in Ontario, Canada providing Intervenor and other specialized services to adults who are deafblind. With residential locations and community services programs across the province, our services extend into a wide range of communities in Ontario.

Our service model ensures our clients goals meet their desires, preferences and abilities through a person-centered approach delivered by specially trained Intervenors.

“Certification provides recognition of the accomplishments of professionals who have reached a high level of expertise”

In 2006, the process began to ensure that all employees working with the clients at DeafBlind Ontario Services learned the important competencies about deafblindness to provide high quality Intervenor services. The result of this process was the implementation of TOUCH™ - Training Ongoing Unique Committed Holistic training. TOUCH™ has gone through



TOUCH training

several updates over the years, with the most recent evaluation being funded by the Ontario provincial government in the fall of 2012.

Today, the organization continues to support the provision of a consistent delivery of training through TOUCH™ towards meeting a professional standard in the field of congenital deafblindness.

It was that objective of meeting a professional standard in service and believing in the profession of Intervenor Services that led to investigating alternatives to support this objective. Over the last two years, we investigated numerous avenues for a professional certification process for employees who have successfully taken the internal training as well as met additional standards.

To designate and certify a training program requires a certifying body to review and ensure quality assurance with respect to the courses required to set standards for the discipline (Intervenor

Services). Prior to any certification and approval, the certifying body must review the course of study, testing procedures, classroom visits and the qualification of the instructor(s).

There are several benefits to the employee who successfully achieves Professional Certification. It illustrates that you are a recognized professional in the field and take pride in your professional standing, having maintained a high level of training and work experience.

We are very excited to share that CCCP Global (Canadian Council of Professional Certification) has accepted, as part of their certification process, our TOUCH™ internal training in conjunction with additional standards. CCPC is a recognized certifying body both nationally and internationally and has a rigorous process and standards by which to measure certification. Certification is granted to professionals working in their specific disciplines who have met the standards set by the organization and a certifying body (such as CCCP Global). As part of the certification process a Standards Manual was developed that outlines the standards and requirements needed towards certification and re-certification on an annual basis.

As a result of this process,

Canada
continued

Deafblind Ontario Services Intervenor will now be designated as Certified Congenital DeafBlind Specialists (CCDBS).

Certification provides recognition of the accomplishments of professionals who have reached a high level of expertise. The professional certification received from CCPC measures skills, practical work hours and knowledge

against a set of standards in the specialized field of congenital deafblindness.

Certification is just one measure of one of our organizations' vision statements "strengthening the competencies of people who touch the lives of individuals who are deafblind". We are proud to offer certification to our Intervenor and are confident it will only lead to

more professionalism and the highest quality service to the people we have the privilege of supporting.

Susan Monahan
DeafBlind Ontario Services
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www.deafblindontario.com
www.facebook.com/
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Twitter:@DeafBlindON

Conference Unlocks Doors to the Future

The 6th annual Deafblind Coalition of Ontario¹ Conference entitled "The Spirit of Intervenor: Unlocking Doors to the Future" was held at the Hilton Markham Suites, Toronto, Ontario, March 4-6, 2013. This year's event was organized by Rotary Cheshire Apartments.

Evaluations and emails flooded in claiming:

- "This was the best one yet!"
- "Never had I left a symposium feeling so inspired!"
- "I have taken so much knowledge and inspiration from the keynotes. Words can't explain what I left with."
- "Great opportunity to get re-energized, inspired, with great networking, Great job!"

This year's event was attended by 275 delegates, speakers, and accessibility staff. Accessibility staff included practising and student Intervenor, practising and student ASL (American Sign Language) interpreters, LSQ (Langue des Signes Québécoise) interpreters and voice over interpreters.

Highlights of the conference include three powerful keynote speakers: Bill Barkeley, Bapin Bhattacharyya, and Pierre Beaudin. Bill Barkeley, is a celebrated outdoor adventurer and vigorous advocate for services for individuals who are deafblind like himself; Bapin is a technology expert/consultant who is deafblind and works for the Helen Keller National Centre in the USA, and Pierre



Beaudin is an Educational Resource Consultant and parent of a young lady who is deafblind. Delegates were inspired, encouraged, entertained, and brought to tears by the very personal stories of these men.

At the plenary sessions, two individuals who are deafblind and their Intervenor shared their own personal stories on how

¹ The Deafblind Coalition of Ontario is a network of agencies dedicated to the sharing of information and the promotion of awareness of deafblindness and Intervenor services in Ontario, Canada.

Canada continued

Intervenor services opened doors to life, communication, understanding, independence, and simply to the many ice cream flavours out there for the taking.

In addition to the keynote addresses, attendees had the opportunity to choose from a varied list of 24 workshop sessions, which included: technology and iPad Apps, deaf-blindness and mental health, stress and conflict management, sexuality, orientation and mobility, oral interpreting, cochlear implants, educational initiatives, and sensory input disorders.

The networking reception was a great opportunity for delegates to meet others and learn more about the agencies providing Intervenor services across Ontario. These agencies showcased their services and special events throughout the conference. At the closing banquet, delegates relived their youth, dressed up, ate decade inspired candy (think Pixie Stix and FunDip) and danced through the decades. Everyone learned how to Stompa, as Ronald Remon led the delegates through choreographed

dance moves intended to get everyone up on their feet, stretch and share as a group.

The conference was funded in part by the Ontario Ministry of Community and Social Services.

Workshop presentations are found on the website: www.rotarycheshirehomes.org.

Renée Toninger,
Conference Co-Chair
Rotary Cheshire Homes Inc.
101-422 Willowdale Avenue
North York, Ontario M2N 5B1
info@rotarycheshirehomes.org

Ireland

Anne Sullivan Foundation and Anne Sullivan Centre

The Anne Sullivan Foundation for Deafblind was formed in 1989; then the only such organisation in Ireland. Following that, The Anne Sullivan Centre was then opened in Stillorgan, County Dublin for a small group of young adults who were Deafblind due to Congenital Rubella Syndrome. The Centre has always been envisioned as "a home for life" by its founders, so that adults who were Deafblind could live amongst their peers and learn important independent living skills while still having the comfort of a home setting. There are currently ten Deafblind adults living at the Centre's four houses which are situated within the local community, while still having close access to the Centre's main building where



they experience a variety of functional and leisure activities such as cooking, music, art, multi-sensory, and physical education/exercise classes.

Outreach Services

For the past two years, the Foundation has been also offering outreach services and training for Deafblind infants, school-age children, and adults throughout Ireland through the consultation of Deirdre Leech. Deirdre is a teacher of Deafblind who came to the Anne Sullivan Foundation after working at Perkins School

for the Blind for 14 years. Providing outreach services to the families and service providers of individuals who are Deafblind around the country supports the mission statement of the Anne Sullivan Foundation to help these individuals achieve their highest potential. Through the outreach services, the Foundation hopes to bring more awareness to the field of Deafblindness as well as the needs of individuals who are Deafblind in Ireland, as it continues to be a challenge in a country which does not recognize Deafblindness as a distinct disability.

For more information,
contact the center at: info@annesullivan.ie or the
website: www.annesullivan.ie
ie; phone: +353 1 830 0562;
fax: +353 1 860 3199

Sense International (India):

India

The Challenge to Support 500,000 Deafblind Children, Youngsters and Adults

Invitation

In the years I worked for Kentalis in The Netherlands I had the privilege to be able to visit my colleagues of Sense International (India) twice, with both visits being very short. On September 15th 2011, I retired from Kentalis. During my farewell party I received a surprising video message from Akhil Paul, director of Sense International (India) (SII) saying: "Ton, now you have the time to come again to India; this time come to visit some of our projects and see the real India".

With that invitation, I flew to New Delhi together with my daughter Janneke almost one year later on November 5th 2012. Thanks to Akhil and his staff, we had the chance to have a wonderful meeting with the staff of SII; visit two Deafblind Units (Ahmedabad and New Delhi) and visit Community Based Programs in different villages in the state of Gujarat and in a few disadvantaged/slum areas in New Delhi.

Meeting the staff of Sense International India

Coming from The Netherlands with a population of 16 million people (as many as there are living in New Delhi), we met colleagues with an enormous drive attempting to support approximately a half million deafblind people living among a population of 1.2 billion people throughout

35 different states, speaking 415 languages. What a huge challenge!

At the time that Sense International (India) started its activities in 1997, only 23 deafblind children were receiving services throughout the country. Recognizing the huge population of India with its enormous cultural and language differences throughout the country, SII decided not to choose a strategy of starting up services entirely by themselves. From the very early beginning they were convinced that a strategy directed on working together with different partners throughout India and supporting them to start up services for deafblind people should be much more successful. And so they did!

Today about 43,000 deafblind individuals are receiving services: 11,000 deafblind individuals are receiving direct services through 45 partner NGO's in 21 states while 32,000 deafblind children are included into mainstream education under the "Education for All" scheme of the Indian Government. To ensure a good quality of teaching for these deafblind children, SII set up a partnership with the government of India. Through this partnership over 2500 government teachers are trained on issues about deafblindness and the appropriate teaching techniques necessary for

deafblind children attending mainstream schools. What a huge difference compared to the number of deafblind individuals reached only 15 years ago! While this is impressive in one sense, still less than 10% of the estimated population of 500,000 deafblind individuals receive this service.

During this meeting we had a lively discussion about the future focus and strategy of SII. Due to the difficult economic situation at this moment, especially in Western Europe (where 60% of their funding is coming from Sense International U.K.), their current strategy is to stabilize the current level of activities. This doesn't mean they can't start up new activities.

One of the most important





Ton Visser

elements in the present strategy is influencing the federal government of India to ensure that the rights of deafblind people are protected and their specific needs are met. SII has been very successful in their campaigns since 'Deafblindness' is recognised as a unique and separate disability in the proposed Disability Bill in India. As a result of this, teachers receive specific training for working with deafblind children in regular mainstream schools.

At the same time our colleagues at SII try to find new partners; stimulate and support them to take initiatives to start services for deafblind individuals throughout the country. In nearly all cases this means providing these partners with information and taking care of staff training. Often it also means supporting these new initiatives financially. Stabilizing these new programs for the long term means that in the future, no new initiative can be supported unless one of

the partners is able to take full financial responsibility for their project. While this fortunately happens for some partners, they all don't succeed in the long run.

The Deafblind Units in Ahmedabad (the Blind People's Association) and in New Delhi (the National Association for the Blind)

In the two weeks following those initial discussions, we had the chance to see different kinds of projects; several supported by SII and one in collaboration with a partner. The following are a few impressions of our visits.

The Deafblind Unit in Ahmedabad is on the campus of The Blind People's Association. About 20 children and youngsters visit the unit daily. Depending on their individual needs, they attend the program for 2 to 5 hours each day. Parents are responsible for the children's transportation.

Two teachers with assistants are working in the unit. One of them has training from Mumbai in one year diploma course on deafblindness. She is responsible for training the other staff members of the unit. As part of the UKAID¹ supported project, one of the hospitals of Ahmedabad recently established an Early Intervention Program together with The Blind People's Association. It was special to discover that the start of this Early Intervention Program was

partly made possible by the experiences learned in the Early Intervention Program supported by Kentalis in Bihar State in Northern India.

The policy of the unit in Ahmedabad is to integrate the children in the regular school system, if possible. Three of the children attending the Centre now are working towards their integration into the regular school system.

It was clear to me that in this Unit there was a focus on total communication. The teachers and children were using objects of reference, calendars, pictures and tactile signing. I realized here at this Unit how much we are all part of an international community working with deafblind children; sharing our experiences.

We were especially impressed with developments in the pre-vocational training program, with its focus on developing individual skills based on each individual's possibilities. In the little 'production chains' where they were making postcards, lamps for Divali², etc., each of the children made input according to their individual abilities. Each young adult demonstrated themselves as a valuable member in the 'chain'. A few of the trainees were not in the Centre that day as they were selling their products for Divali in a shopping centre.

In New Delhi the **National Association for the Blind** started the Deafblind Unit in cooperation with SII in 1999.

¹The UK Department for International Development (DFID) is the official development agency of the Government of UK managing aid for the poor, developing countries. (www.fundsforngos.org)

²Divali, popularly known as the "festival of lights," is a five-day Hindu festival. Wikipedia

During our visit, 50 deafblind children were visiting the unit for the entire week, while 11 children were visiting only on Friday's. The unit also coordinates the program of 22 deafblind children who are following the Community Based Program in one of the disadvantaged areas of New Delhi.

Specialized teachers who have graduated from the diploma course on deafblindness in Mumbai or Chennai are teaching in the deafblind unit. The children are organized in four different levels: playgroup (3-8 years), functional education (9-14 years), pre-vocational training (14-18 years) and vocational training (18-21 years). For each of the children there is an Individual Educational Plan (IEP) which is evaluated every three to six month and adapted according to the child's progress. There is an emphasis on "learning in the situation" like in shops, marketplaces, etc. for those in the pre- and vocational training levels.

What stood out in this deafblind unit was the strong cooperation and participation of the parents. The deafblind unit organises workshops for parents together with the Association of Parents on a regular basis and is providing support in the home situation when needed. Parents are always invited to contact the deafblind unit with any question.

The Community Based Programs in Gujarat and in New Delhi.

Very early in the morning of November 7th Akhil picked us up for a long drive to visit different villages in Gujarat to meet clients who receive services under the Community Based Rehabilitation Program (CBR) by Ashirwad Trust for the Disabled³ and SII. On our way to the first client we picked up Mr. Dipak, the fieldworker whose clients we would meet.

Our first stop was in the village of Hansa to meet a 22-year young adult living together with her father and mother. When Mr. Dipak started working with Hansa she was nearly all the time sitting in a corner of the house or lying on the floor. The development of Hansa in the last 12 years, which included seven years attending a regular school, could be best described in terms of 'from isolation to participation'. We met a young adult communicating through total communication (finger spelling, signing and using written large letters on paper and in her hand) and taking care of almost all of the tasks that has to be done in the house by herself. Most impressed we were to see that other children from the little village were able to communicate with Hansa. Her father told us that they include Hansa in their activities without any thought about her handicaps. Dipak indicated

that his support of Hansa was greatly supported by her parents as well as some people from her village. Currently her mother is teaching Hansa complex cooking skills.

Our second stop was in Limbdi where we met Mr. Rajesh Sheth, 34 years old and totally deafblind. He had attended a school for deaf children when he was younger and learned sign language. Several years after losing his vision he started receiving support from Mr. Dipak. Together they focussed on self-help skills at home, mobility skills (since he lost all his mobility skills), communication (a re-introduction to sign language, handwriting, using email) and re-establishing contact with his friends. He is now able now to take full responsibility for his part in the home; is easily able to switch communication modes; produces sweets and runs a shop for sweets, and has re-established contact with his friends. His friends are communicating with him by handwriting and email. They pick him up where ever they go. His mother said: "together with SII and the Community Centre of the Ashirwad Trust for Disabled we are a chain, nobody can be missed to make this possible for Rajesh!"

Before returning home, we were invited to the Community Centre which coordinates all the activities of the fieldworkers in this region. At the moment they

India
continued

³Ashirwad Trust for the Disabled (ATD) was founded by the divine inspiration of Param Puja Bhaishree Nalinbhai Kothari of Shree Raj Saubhag Satsang Mandal, the professional consultation and advice of the Blind People's Association, Ahmedabad and the needs voiced by thousands of blind and disabled persons in the Surendranagar District. (www.ashirwadsayla.org)

India continued

are serving 27 deafblind children. They have a list of 20 deafblind individuals in this district they cannot help at this moment due to a lack of resources. Apart from coordinating the services and training their own fieldworkers, the Community Centre is organising, in cooperation with SII, summer camps for their clients together with their fieldworkers. Three times a year they coordinate workshops for parents. One of the strengths of the program is undoubtedly that they include the community i.e. parents, neighbours and friends.

“We met so many dedicated and skilled colleagues during our travels that encouraged us to believe that this service will inevitably be expanded”

In New Delhi we had the privilege to meet four deafblind children in their home situation: three boys (two of them are brothers) with severe physical impairments and a girl with challenging behaviour. Not all of the deafblind children identified in New Delhi attend the deafblind unit, for different reasons. The best choice appears to support them in their home situation since the parents simply don't have the resources to drop off and pick up their children; also their physical impairments make it too complicated for transportation.

The deafblind unit's

support system is very well organised. The fieldworker has regular contact with Unit and attempts to visit the deafblind children twice a week.

In conclusion

First of all it was an enormous privilege to be able to meet our colleagues of SII and their partners, observe their work and have very useful discussions.

Their strategy to focus on partnerships to develop services for deafblind individuals is without any doubt very successful. I have seen very few organisations which were so successful in reaching 43,000 deafblind individuals in only 15 years while being so cost effective. When determining services for these individuals, there was no consideration of such ideological issues as mainstreaming versus specialised/centralised education and services. SII suggests what they think will work best for each deafblind individual or group, depending on the particular situation. This includes: integration in the regular school system, education in specialised units, education and training in Community Based Programs in outlying villages or in disadvantaged neighbourhoods of large cities.

We were most impressed to see the impact on the lives of the deafblind children, youngsters and adults that we met through the support of SII and their partners. It was wonderful to observe how involvement in the Community Based Programs often leads to

real participation in their communities. This is rarely seen in Western European countries.

Having said this, SII faces incredible challenges in the coming years. Coming from The Netherlands, it seems like an incredible number to have been able to reach 43,000 deafblind individuals. However this still represents less than 10% of the estimated population. It will require a very balanced strategy of supporting the current program level (quality and quantity), expanding new partnerships and insisting that Governments take full financial responsibility for creating spaces for more individuals.

We met so many dedicated and skilled colleagues during our travels that encouraged us to believe that this service will inevitably be expanded to include many more deafblind individuals in India. How wonderful it will be to offer so many more deafblind individuals, who still live in isolation, the opportunity to participate with their family and in their community.

With the wonderful image of deafblind children, youngsters and adults communicating with their neighbours in their communities, we flew home!

**Ton Visser and
Janneke Visser
asmvisser1948@gmail.com**

Ton was formerly the Managing Director of Training at Royal Dutch Kentalis, the Netherlands. He served as Treasurer of Deafblind International until 2009.

Stories of Change¹

India
continued

Stories about the impressive development demonstrated by three boys with various levels of sensory and physical impairments through the support of staff from the Society for the Visually Handicapped in Kolkata, India

The Society for the Visually Handicapped (SVH), a registered non-government organization in Kolkata, India was founded in 1983 to provide education resource support to visually challenged persons in their higher education. The Project Deafblind was taken up to provide home-based life-skill training to the children with deafblindness and multiply disabled visually impairment (MDVI) in 2004. Trained educators were recruited to impart the specialized training. Starting with two children and one untrained social worker, Project Deafblind now has 6 educators who are engaged in training and supporting 42 Deafblind and MDVI children and young adults in Kolkata and surrounding areas. Two of the educators were sponsored by Sense International (India) for the Diploma Course at Helen Keller Institute for the Deaf

and Deafblind, Mumbai². However, one of them has left the job.

SVH, a premier organization in the field of disability, is a partner with the government of West Bengal in its programmes on “inclusive education” for persons with disabilities.

Initially the challenges before SVH were the uncertainties of enrollment of these children in local schools, because of their inherent “inabilities” to perform like other children of the same age. Secondly, there was no role model to follow, since SVH is the only institution in West Bengal to work with the persons with deafblindness and MDVI. Consequently we concentrated on the Individual Education Plan (IEP) and kept the periodic records of development for each child. A careful and sustained implementation of IEP for 4-5 years had

transformed most of the “inabilities” of the children into abilities. Gradually we planned for inclusion of some children in mainstream schools with the parents’ cooperation.

Here we want to focus on 3 children who are attending general school in their localities and taking part in regular school activities. These children posed challenges before us in the initial years of their enrollment into SVH Project Deafblind.

9 years old **Joel Murmu**, stays with his parents in Dum Dum, north Kolkata. He has Cerebral Palsy, vision impairment with speech problems, and was hyper-active. Joel was enrolled with SVH in September 2007. Joel’s parents, Snigdha and David, were eager to give him the support so that he can acquire life-skills and they agreed to bring him to SVH Deafblind Resource Centre,



¹ Paper presented at the 2nd Joint ICEVI-DbI Asian Conference, April 5-7, 2013, Ahmedabad, India

² www.helenkellerinstitutefordeafanddeafblind.org



although the distance from their residence is almost 25 kms. In the initial years, Joel came to the Centre once in a week and our educator gave training at his residence once in a week. The Impact of initial training was that Joel's hyper activity was reduced. He liked to work with the educator and also his speech was gradually becoming clearer. At this stage, in 2009, he was admitted into a local kindergarten school. Considering his requirements, SVH then enhanced the home-based training to two days in a week.

In 2010 Joel was enrolled in North Point School, a mainstream secondary school. Now he is in class III. He is very much comfortable with his class teacher and peer-group. Braille has been introduced to Joel. Due to his fine motor problem, Joel uses the adapted stylus. At present, he knows the English alphabet and numbers in Braille. For diagrammatic representation he uses tactile outlines. Due to sustained vision stimulation in all these years, he is able to use his functional vision. He loves to colour pictures by touching the raised outlines.

Joel is fond of music and is a good singer. Now he gets training in playing table and guitar. In all the school activities, Joel finds a place to perform. In SVH annual programmes, we encourage him to take part. The parents of other children, who have seen his achievements, now cherish the dream of their wards' future. This definitely brings attitudinal change in parents!

Sourav Sarkar was referred to SVH in 2008 by a physiotherapist at the Indian Institute of Cerebral Palsy³ (Kolkata). The family resides in a slum in Tollygunge, south Kolkata. His mother Saraswati is employed as domestic help and remains out of house for the major part of the day. His father Sanjib is a casual worker in building construction. Eight years old Saurav Sarkar stays in a slum in Tollygunge, with his parents. He has congenital cataracts, bilateral severe hearing loss with speech impairment and is diplegic⁴.

The initial training took place at his residence, in a very small room. At that stage Saurav could crawl to move from one

place to another. We first introduced him to gaiter⁵ for both feet to allow him to stand by holding parallel bars. With our consultant physiotherapist's instruction afterwards, SVH provided an AFO (ankle-foot orthotic) and wheeled walker to him which helped him to move about with minimum assistance.

In 2010 Saurav showed remarkable developments after his bilateral cataract surgery; he became partially sighted with the use of spectacles. By observing his visual developments, his mother Saraswati became motivated to follow the teacher's instructions, and left her work service to bring her son to our centre for vision and tactile stimulation. This proved very much beneficial for him. He was taught to express his preferences through playing and shopping activities. He started showing his preference by finger pointing. However he is yet to learn communication through sign language. In 2011, he received admission to the local municipal school. Since then, Saurav has developed a positive interaction with

³www.iicpindia.org

⁴When used singularly, refers to paralysis affecting symmetrical parts on either side of the body. (www.en.wikipedia.org)

⁵A cloth or leather covering for the instep and ankle. (www.bing.com)

his teachers and peers. He is able to take part in various group activities of his class. Due to the lack of proper infrastructure in the municipal school, he is now attending the Circle Resource Centre for the children with special needs located near his residence. This centre is maintained by the Sarva Shiksha Mission⁶, a Government of India education programme in Kalkota. Saraswati takes him to the centre on the allotted days. I, myself as educator of Saurav, provide him additional support to continue with the school curriculum. The mobility training has helped him to move around independently. He can now climb up stairs of the SVH Centre by holding the stair rail. In 2012 Saurav happily participated in a drama rehearsal and followed the instruction of the trainer.

Deep Gosh, a boy of 11 years staying with his mother in a village named Kulgachhia in Howrah, was referred by Howrah Sarva Shiksha Mission⁷, in 2010. He has Congenital Rubella Syndrome. Recently he has been diagnosed with juvenile diabetes. During that time, he was studying in class III in his village primary school. Due to his low vision, mild hearing loss and speech problem, he was unable to communicate his needs to his teachers. His communication problems had not only affected his studies, but segregated him from his peers in the school as well as in the community.

Our concern was to create a situation so that he can continue in school education and take part in school activities. SVH allotted the task of need-based support for Deep to teacher Biswajit Chakraborty. This definitely put a pressure on SVH faculty, as Deep's residence was outside the SVH orbit, and this assignment made Biswajit unable to work for any other child on that day. It takes four hours train journey to reach Deep's house/school, with one change in train, and availing any other local transport service. The return journey also takes the same time. Biswajit started visiting Deep's house once in a week from January 2011.

Deep's speech improved very much with some aural-motor training, like blowing balloons or paper, making soap bubbles, etc. Since language skill was not properly developed, Biswajit put emphasis on simple word making and pronunciation, leading to sentences. Presently, he is very much comfortable with his peer group and can take part in various group activities with sustained training; all these have improved his academic performances. He can follow class instruction & can appear for oral and written examinations with some adaptations; he uses dark border line, black pen, and exaggerated speech, etc. Besides these, Deep is fond of drawing pictures of his environment. Finding this potentiality in him, we provided him the support

from a professional trainer.

SVH is committed to enhance the capacities of these three children so that they can continue their school education. For Joel and Deep, we are planning to introduce them to computer education and use technological devices, since both of them are of low vision. As Deep is fond of painting, we support him for his drawing classes, and think about diversifying this skill in other artistic activities. Joel is a good singer, and loves to play the indian drum Tabla. Besides academic learning, these other skills need to be enhanced in future. We are careful in providing Saurav other skills beside formal academics, because of his family's economic condition. He has been introduced to mala (flower garlands) making through plastic flowers. Our aim is to lead him towards costume jewellery-making in the future.

We are exploring other activities for these three boys so that a proper "transition planning" can be adopted at their right age. Although we have brought them into the 'Inclusive Education', they have a long road ahead of them which will not be smooth but the progress so far promises a lot for their future.

**Mallika Das, Special Educator
Project Deafblind, Society for
the Visually Handicapped
www.svhwestbengal.org**

**India
continued**

⁶www.ssmkolkata.tripod.com

⁷www.ssmhowrah.org

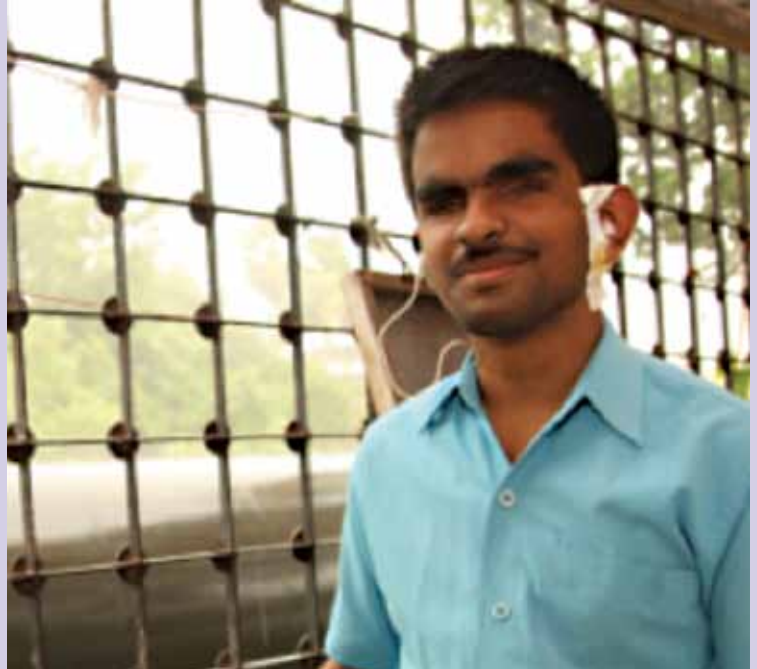
India
continued

Two Parents start a school and create a Community of Hope

“What will happen to our child once we are gone?” wondered Prakash and Usha Bal, parents of a child who was born blind and with severe autism in a northern suburb of Mumbai, India. “That was our wake up call,” said Usha.

That wake-up call led the couple to establish the SOBTI Vocational Training Center in January of 2007, the first school in the region to accept children who have multiple disabilities. At SOBTI – the name means companion in Hindi —the primary focus

SOBTI students, parents, and staff return to the Center after visiting the market



is on vocation and life skills trainings. Students learn to create numerous items including artificial jewelry, seasonal food items, candles, and greeting cards.

Perhaps the greatest key to success is the involvement and partnerships that the teachers and students have with the parents, said Prakash Bal. Not only do the parents learn important ways to communicate and interact with their own child, but they play a key role in teaching life skills to all the students. This includes weekly outings where they take the students to many

places in the city via public transportation. Whether the goal is to go to the market and buy vegetables or simply to make students more aware of the outside world, the result is an increase in independence, confidence and sense of responsibility for all the students.

SOBTI was the answer for Gaurav Vijay Singh, who, at 2 years old, had lost both eyes due to cancer. Like many of the students at SOBTI, Gaurav was accustomed to being turned away from schools. By 2006, at the age of 12, Gaurav and his

“Perhaps the greatest key to success is the involvement and partnerships that the teachers and students have with the parents”

India

continued

parents had all but given up on his education when teachers from the National Association for the Blind (NAB)—a Perkins partner organization—arrived at their home. The teachers recognized Gaurav's capacity and desire to attend school and they knew exactly where to send him.

Today, 18-year-old Gaurav is a star student at SOBTI. He is in grade seven and he can read and write braille. Gaurav shops and cooks on his own, and he dreams of going to college and becoming a doctor.

The success of students like

Gaurav has led to SOBTI's recent growth. In 2010, in order to meet the increasing need for a center in the western suburbs, Perkins International financed the establishment of a second center and NAB offered them a space they could use at nominal rent. Both SOBTI centers continue to work in close collaboration with the NAB.

Thanks to the Bals' commitment, the overwhelming dedication of the teachers, and the SOBTI Parents Association, many parents of children with multiple disabilities

now possess the comfort of knowing that their child has a secure future. The story of SOBTI is truly the story of a successful partnership, said Usha Bal.

"Perkins gave us the training," she said, and "NAB gave us the inspiration."

www.perkinsinternational.org/success_stories

www.perkinsinternational.org/success_stories/two-parents-start-school-and-create-community-hope?
Reproduced with permission from Perkins School for the Blind



SOBTI students visit the local market and explore the produce

Japan

Towards disability and development:**A Report of the Asia-Pacific Regional Consultation**

The United Nations convenes a High-level Meeting (UNHLM) on various subjects before the UN General Assembly every year. The UNHLM this year in New York will be held September, 23, 2013 with the theme, 'Disability and Development'.

There are many UN conventions, statements and other internationally agreed development goals, but few of them mention disabilities and their specific needs. This is true also for the Millennium Development Goals (MDGs). Within the UN, there has already begun a discussion about their development agenda towards 2015 and beyond. Without a doubt, we strongly believe that persons with disabilities should be recognized in all aspects of these discussions.

To prepare for the 2013 UNHLM, regional consultations are being organized in Africa, Europe, South America and in the Asia-Pacific Region. Consultations in the Asia-

Pacific Region convened 15-16 May 2013 at the United Nations Conference Center, Bangkok, Thailand, with the theme 'The Way Forward: Asia-Pacific Regional Consultation on a Disability-Inclusive Development Agenda towards 2015 and Beyond'. The outcome of this consultation will be presented to UNHLM September 23, 2013. I am happy to report about the recent consultation meeting.

The Asia-Pacific regional consultation process consisted of senior representatives from governments, disabled people's organizations, civil social organizations (CSO) and other international organizations from the region. The World Federation of the Deafblind (WFDdb) was officially invited to this meeting as one of the CSOs. Shinichiro Kadokawa from Japan (SMILE) was present as the official WFDdb representative from Asia.

The objectives of this consultation were two-fold: first to provide an

opportunity for the Asia-Pacific governments and relevant stakeholders to exchange views on disability-inclusive developments; second, compile these regional inputs for inclusion in the draft outcome document to be presented at the September UNHLM. This consultation process was organized by the Royal Thai Government, in cooperation with the Australian Government, the Economic and Social Commission for Asia and the Pacific (ESCAP) and the World Bank.

The Consultation Process

On the first day of the Consultation meeting, the group discussed the working report called the 'Draft Bangkok Vision' which was prepared by the Secretary for ESCAP and received in advance by all participants. The draft vision became the focus of discussion by all the participants, WFDdb and World Federation of the Deaf (WFD) during the first day.

First, it is necessary to point out that all the participants had an opportunity to speak at this meeting, but the right to vote on the final wording is only carried by senior representatives from the governments. It was very important for individual participants with disabilities not only to appeal for their



Shin (middle) and Akemi (right)

Japan
continued

own individual specific needs but also to negotiate with other organizations to encourage governments to adopt 'the voices of those of us who are challenged or who have disabilities' and organize a consensus of thoughts and ideas in the final report.

In the initial Bangkok Vision discussion paper there was a statement prescribing Universal design¹ and accessibility as follows:

"Incorporate universal design in and ensure the full accessibility of, all of physical environment, public transportation, as well as the knowledge, information and communication infrastructure, and services for the public."

We were not happy about these initial statements as we felt it was not enough to meet the Information and communication needs of people with deafblindness. Shin, standing up for the 'voices of the unheard' who face challenges of information and communication, made the following significant points during the first day of discussions:

- Article 21, Convention on the Rights of Persons with Disabilities (CRPD) addresses and ensures the right to freedom of

expression and opinion;

- Accessibility has two distinct aspects which are visible as buildings and transportation and invisible as information and communication.
- CRPD defines communication in Article 2 and mentions that sign language is the language of the deaf; the importance of sign language is indicated in the Incheon Strategy² which provides the Asian and Pacific region, and the entire world, with the first set of regionally agreed disability-inclusive development goals.
- To ensure the accessibility of information and communication, an appropriate budget is necessary. (Shin acknowledged that AusAID provided the financial support to enable the participants to attend the meeting.)

Then Shin together with representatives from WFD and Inclusion International³, made a joint statement based on some of the original draft, Shin's proposals and other discussions.

On the second day, the participants reviewed the second draft produced following day one.

The second draft report

included the following statement regarding **Enhance access to the physical environment, public transportation, knowledge, information and communication:**

"Incorporate universal design in, and ensure the full accessibility of, all of the physical environment, public transportation, as well as the knowledge, information and communication infrastructure, and services for the public. Facilitate the use of assistive technologies. Provide reasonable accommodation. Strengthen access to services and technologies for enabling communication by and with deafblind persons, deaf persons, hard of hearing persons, as well as persons with other types of disabilities."

Again this statement (above) in the second draft **did not** reflect their proposal and original statement.

Shin continued to speak out by emphasizing their proposal and the joint statement. Through further discussions, a revised proposal was developed by Shin and a WFD participant, which eventually achieved support from the other CSO members. One of those supporters was Mr. Monthian Buntan, Senator, Royal Thai

¹ Universal design refers to broad-spectrum ideas meant to produce buildings, products and environments that are inherently accessible to older people, people without disabilities and people with disabilities. From Wikipedia, the free encyclopedia.

² www.unescap.org/publications

³ Inclusion International is a global federation of family-based organizations advocating for the human rights of people with intellectual disabilities worldwide. <http://www.inclusion-international.org/about-us/who-we-are/>

Japan continued

Parliament and Member Committee on the Rights of Persons with Disabilities.

The controversial article was elaborated the below. *“Enhance access to the physical environment, public transportation, knowledge, information and communication: Ensure the full accessibility for all of the physical environment, public transportation, as well as the knowledge, information and communication infrastructure, and services for the public, by incorporating universal design, facilitating the use of assistive technologies, and providing reasonable accommodation. Strengthen access to services and technologies for enabling communication by and with persons who are deaf, deafblind and hard of hearing, as well as persons with other types of disabilities, through the provision of sign language, tactile communication, Braille and easy-to-understand materials, among others”.*

Through further discussions, a revised proposal was developed by

Shin and a WFD participant, which eventually achieved support from the other CSO members. One of those supporters was Mr. Monthian Buntan, Senator, Royal Thai Parliament and Member Committee on the Rights of Persons with Disabilities.

At the end of the day the final report which included Shin’s final statement, various amendments from various regional governments, organizations and persons with disabilities became the Bangkok Consensus which will be presented at the UNHLM in New York in September 2013.

The Bangkok Consensus

There was general consensus among the participants that the consultation document prescribes the following required actions for inclusion developments:

1. Reduce poverty and enhance work and employment prospects;
2. promote participation in political processes and in decision-making;
3. enhance access to the physical environment, public transportation, knowledge, information and communication;

4. strengthen social protection;
5. expand early intervention and education for children with disabilities;
6. ensure gender equality and women’s empowerment;
7. ensure disability-inclusive disaster risk reduction and management;
8. improve the reliability and comparability of disability data;
9. accelerate the ratification and implementation of the Convention on the Rights of Persons with Disabilities and the harmonization of national legislation with the convention, and
10. advance subregional, regional and interregional cooperation.

Nothing about us without us, a very famous slogan which came from the process of CRPD, was practically carried out in Bangkok.

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“Within the UN, there has already begun a discussion about their development agenda towards 2015 and beyond. Without a doubt, we strongly believe that persons with disabilities should be recognized in all aspects of these discussions”

"Multiple disabilities and deafblindness" online course – 2012

Mexico



The Mexican Secretary of Public Education, through the national office of support for state programs in Special Education and financed by Perkins International, offered in 2012 for the third year an on-line training course on Multiple disabilities and deafblindness to special education staff and parents of children. This course, which includes 120 hours of instruction and discussion groups offered over a five month period, has to date reached 300 parents and professionals in 38 states of Mexico as well as in Colombia, Peru and Bolivia. This course is delivered through a platform donated by the Office of Special

Education in the Capital District of Mexico (sep.pdf.gob.mx).

In Mexico the course is delivered by expert tutors previously trained by Perkins International. Each tutor works with a maximum of 20 participants. In 2012, 80 persons were admitted into the course from 200 applicants. For the first time 7 parents were included in the training. Also important was the participation of several statewide consultants of special education who are responsible for training and staff development of services in their respective states.

Two comments from participating MOTHERS:

"My infinite gratitude for allowing me to participate

in this great course!! I would be lying if I said that it was not a lot of work. I am a single mom, no degree. But I am always up for a new challenge and this was worth my effort. You succeeded in meeting my expectations...."

"Thank you for all the support to the whole group, because in my case this is new and there were many terms and words that I didn't understand. You explained perfectly and every time I received that patience and support of the tutor. I only finished this course because of the support from you!"

It is important to note that in this course there were a number of state special education consultants who have offered to replicate this information to local school districts and regional services. Many of the special education centers have no information on this topic. The participation of these state consultants added a different dynamic to the course as they do not work directly with children. Some used the time to identify individual children who are Deafblind or with multiple disabilities, applying the skills



Mexico continued



they learned from the course. This experience has shown the need to continue to reach out to the supervisors in each state to expand the impact of the on-line learning.

Some comments from the state consultants:

"It is very important to recognize had little knowledge of this type of disability and the need to know strategies to advise staff of regional special education centers was obvious. During the course the learning of specific methods and strategies led me to the development of new projects to be carried out in the coming year."

"The course is very rich and interesting, in my case it has allowed me to expand the knowledge to care for the students, shared with the teachers and principals from my advisory role. The opportunity that we had to share the experiences of colleagues in other States of the Republic already allowed me to not feel "alone" in

addition to the possibility of creating a network of professionals. I appreciate the opportunity given to me to participate and receive the training by this means which enables us to update us in the profession."

This is an example of the many observations of the teachers on the course:

"After living this experience I have the need to continue preparing myself on the subject, seize me more strategies to respond to the specific needs of the students we serve, and above all starts the real challenge move everything learned to my context and contagious enthusiasm that characterized the group that work with my colleagues in area to carry the light of hope that students with multiple challenges can be independent, self-sufficient, lead a full life within the society."

Based on the analysis of questionnaires completed by the wide range of participants, the following

were the most significant aspects learned during the online courses:

- Everything that relates to the human rights of persons with disabilities; comparing with the laws of the various Mexican States and the United Nations Convention
- Etiologies, and characteristics of multiple disability and deafblindness
- Person centered planning
- Alignment of the functional curriculum with the national curriculum
- Transition to adult life
- Communication maps
- Sensory Integration
- Alternative Communication
- Functional Assessment

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Thanks to Steve Perrault
for assistance with the final
English translation

'I retrieved my identity'

Netherlands

Charlotte van de Molengraft (64), from Eindhoven (the Netherlands), once a sighted person became deafblind. This is why she is following the Tactile Training and Creativity Development Program at Kentalis¹. This is an updated training course that provides Charlotte with the opportunity to be creative and develop her sense of touch.

If you can't see, you have to do everything by touch. "I had to learn this," says Charlotte. "I started out by putting together small pieces of work. At first, I often doubted myself and thought-I can't do this. In fact, I thought I could not do anything anymore. But by doing it anyway and thanks to the support I received

from the supervisors (at Kentalis), I now realise that almost anything is possible if you set your mind to it."

Small pieces of work developed into beautiful works of art. "I can do much more by touch now, which is very useful in daily life. My ability to do things independently and my self-confidence have improved greatly. I am better able to show my emotions and process impressions; I have retrieved my identity."

Charlotte follows the training course in a group of six to eight deafblind people. "It is very informative: they learn things from me, as I learn from them. This also allows me to keep up my common-or-garden signals and learn new words. We talk about problems and

questions, such as household issues."

Charlotte has made many works of art, such as mosaic paintings, clay dolls, dolls clothing, pots and paintings. "I did a painting with flowers from Brazil, where I once visited. Creating this painting was a double experience: I learned how to work with new material and was able to process the impressions of my journey and make them tangible, because looking at pictures is no longer an option for me."

"I really recommend this training course. I know the satisfaction it brings when you make something beautiful. And maybe more importantly: this course improves your self-esteem."

Charlotte van de Molengraft



¹ Kentalis is a national organization in the Netherlands providing diagnostic, care and educational services to people for whom the ability to hear or communicate is not a matter of course. www.kentalis.nl

Romania

Mini-typography workshop for deafblind children opened in Bucharest



Sense International (Romania), in partnership with the Special School for Children with Hearing Impairments "Sfânta Maria", organized the official opening of a mini-typography workshop within the school in Bucharest on May 29, 2013.

It was an event full of light, colour and sound, where deafblind children and youngsters, together with their parents and grandparents, guests and teachers, enjoyed this special achievement together. The mini-typography workshop, equipped as part of the project A SENSE FOR LIFE, implemented by Sense International (Romania), Bucharest School Inspectorate, Special School for Children with Hearing Impairments "Sfânta Maria" and Bucharest Town Hall, Sector 6 and funded by Orange Foundation, means

for these children "a dream come true, a chance for a better future", as described by Mr. Dumitru Cioiu, father to one of the project beneficiaries.

Youngsters will discover the secrets of digital printing and they will learn how to use the special equipment (binding machine, manual stapler, electrical guillotine, professional photocopier, computer) to produce various printed materials – from business cards to flyers and from booklets to magazines.

The workshop's direct beneficiaries are deafblind/multisensory impaired children and young people, pupils of the Special School for Children with Hearing Impairments "Sfânta Maria", who will acquire the necessary skills and knowledge in the field of digital printing, so that when they graduate they will have increased chances to find a

job and lead an independent life.

Mrs Cristiana Salomie, Director of Sense International (Romania) emphasised the importance of "collaboration, working together so that this workshop becomes functional, useful both to young people learning a new trade and to the community which may use the services of the digital typography".

The host of the event, Mrs Florica Stoica, Director of the Special School for Children with Hearing Impairments "Sfânta Maria", thanked all those present, especially the beneficiaries and their families.

This workshop is part of a larger scheme, a project implemented in Bucharest, Galati and Iasi, benefitting from a financial support of 50,000 Euro from Orange Foundation¹.

Edited Press Release,
May 30, 2013

For more information,
contact: Cristiana Salomie,
Director Sense Interna ional
(România)
www.surdocecitate.ro; email:
csalomie@senseint.org.ro



¹ Orange foundation's mission is to create links between individuals, and in particular to make communication easier for those who are excluded for several reasons; health, handicap or because of their economical situation. (www.fondationorange.com)

Independence blooms from a simple piece of fabric

South
Africa

When customers at a small boutique in Pietermaritzburg, South Africa, purchase colorful fabric flowers or creatively designed cards, they probably have no idea that those items were made by a 17-year-old girl who is deafblind and in a wheelchair.

That girl is Alicia, a student at the Arthur Blaxall School for children who are blind or deafblind. About 200 students, ages 5 to 19, attend.

Like many of her fellow students, Alicia took a class where she learned how to sew, using only her very limited vision and her sense of touch. That skill, along with encouragement from two special teachers, transformed Alicia's life.

However, sewing might have remained just a hobby for Alicia if not for Winsome Bukus, a longtime teacher at the school.

Bukus is a graduate of Perkins' Educational Leadership Program, which

teaches educators from around the world how to more effectively work with children who are blind with additional disabilities. Bukus recognized Alicia's intelligence and urged her to study hard and believe in herself.

Two years ago, Bukus established a fundraiser called "Dinner in the Dark," where he invited members of the Pietermaritzburg community to eat a three-course dinner without the benefit of sight or hearing. The event raised awareness about the challenges faced by people who are deafblind.

Tragically, Bukus died in 2012, so that year's dinner was dedicated to her memory. Each of the 300-plus guests received a blindfold and earplugs in a special gift bag, made from delicate chiffon fabric, sewn by students from the Arthur Blaxall School – including Alicia.

Sitting in her sewing class, Alicia carefully guided the sheer, silky fabric through



This is Alicia, a student at the Arthur Blaxall School for children who are blind or deafblind

a sewing machine to create gift bags for the memorial dinner. Her teacher Fiona Parker observed Alicia's gentle touch and accuracy. Parker is also a graduate of Perkins' Educational Leadership Program, and, like Bukus, recognized Alicia's potential.

Parker returned the next day with a fabric flower constructed from cloth and a button. She carefully took the flower apart and guided Alicia's hands through the process of making it. After learning that Alicia's mother owned a sewing machine, Parker began acquiring scraps of fabric and old buttons from a friend's clothing company. At the end of each school day, Alicia took the materials home and went to work sewing flowers.

Over the course of four months, Alicia made more than 300 flowers and with help from her parents, persuaded a local boutique to sell them. She broadened her inventory to include cards she designs and draws



Students at the Arthur Blaxall School show off the beautiful chiffon gift bags they sewed

South Africa continued



herself. She also started taking orders for gift bags for local birthday parties.

Inspired by Alicia's success, the Arthur Blaxall School is now expanding its efforts to teach other students vocational skills that will allow them to become more self-sufficient.

One teacher, Corinne Pillay, is developing a functional curriculum that will give students more opportunities to develop skills in a natural environment. For example,

a trip to a local market will allow students to practice mobility, communication and counting skills. Pillay, who attended the Perkins Summer Institute, is also working to expand vocational training for students. The school's staff hopes that their new focus on real-world and vocational skills will open more doors to jobs and independence for students.

For Alicia's family, the sight of their daughter hard at work with her mother's

sewing machine is clear evidence of the benefits of a good education and vocational training for students who are blind or deafblind.

"My daughter now has a skill to make a living," Alicia's father said proudly. "I want to thank the people at Perkins. Thank you for helping these teachers give my daughter more skills and a future."

See more at: http://www.perkinsinternational.org/success_stories/independence-blooms-simple-piece-fabric#sthash.ut4IBY0s.dpuf



Winsome Bukus encourages one of her students at the Arthur Blaxall School for children who are blind or deafblind, located in Pietermaritzburg, South Africa



Fiona Parker hard at work developing a new functional curriculum

Passable Landscapes



Children with Usher Syndrome must be equipped to manoeuvre in 'passable landscapes'. New Danish research by Jesper Dammeyer Ph.D., in cooperation with educational consultant Bente Ramsing, shows that more than half of all children with Usher Syndrome develop symptoms of psychosocial dissatisfaction before the age of 18.

By Bente Ramsing (bero.rn.dk), educational consultant, Center for Deafblindness and Hearing Loss (CDH), Aalborg, Denmark (www.cdh.rn). Translated from Danish by Dea Birgitte Hansen and Marie Herholdt Jørgensen, The National Board of Social Services (SOCIAL STYRELSEN)

The research supports practitioners' experience of the development that the consultants at Center for Deaf-blindness and Hearing Loss typically observe in children with Usher Syndrome. In the following, I will provide a description of the functional issues I have been observing in practice, and I will give a number of suggestions as to what parents and professionals may do in order to support a normal development in a protected educational environment.

Usher Syndrome

Usher Syndrome is a recessive inherited syndrome, inherited from both parents. Mostly, the parents are healthy with the syndrome hidden in their genes. The parents are often unaware of the fact that the syndrome is found in their families. There are three types of Usher Syndrome which cover at least nine different subtypes. Usher Syndrome type 1, which covers most of the nine subtypes, is the most pervasive. I mainly focus on type 1 in this article.

At the time of the study we knew of 20 children under 18 with Usher type 1 in Denmark. An

individual with Usher Syndrome type 1 is born with severely reduced hearing or born entirely deaf. The person also has the eye disease Retinitis Pigmentosa and serious difficulties with vestibular processing.

From deaf to hearing-impaired

In Denmark deaf and severely hearing-impaired children, including children with Usher Syndrome type 1, are offered a double-sided Cochlear Implant within the first year of life. The Cochlear Implant, usually called CI, is an advanced hearing aid which is operated directly into the cochlea of the ears. Formerly, people with Usher Syndrome type 1 in Denmark always used sign language; but within the last 10-15 years almost all children in Denmark with Usher Syndrome type 1 have had a double-sided CI, and most of them have developed their spoken language satisfactorily.

The fact that the children have spoken language and are integrated into the hearing world poses them with great challenges, as they are still deaf in many contexts, e.g. in very noisy surroundings, in swimming facilities, at night and in other

situations, where CI cannot be used or does not function as normal hearing.

The eye disease Retinitis Pigmentosa

The eye disease Retinitis Pigmentosa is also called RP or tunnel vision. RP is a progressing disease in the retina with a slow loss of sight. Many RP patients contain a little residual eyesight in the central vision their entire life, while others go blind during their adult life. The retina is affected from the outside in, and the person at first loses their navigational sight and the ability to see in poor lighting.

A severe sensitivity to light often means that the child, already as a newborn, will need to wear a cap and/or sunglasses. It often takes the eye several minutes to adjust to changes in the light, and every time the light changes during the day, the person will lose the ability to see properly for minutes at a time.

The vestibular sense – balance and loss of energy

The body uses the vestibular sense for receiving signals about how it is situated in relation to

“Children with Usher Syndrome use a lot of energy every day because their senses work overtime, and sometimes their energy runs out”

its surroundings. As consultants we often observe that children with Usher Syndrome have hypo-toned muscles, which, combined with poor or no vestibular sense, causes difficulties with movement and balance, which are at first manifested in a developmental delay regarding sitting up, standing and walking. The children struggle with the task of making their reduced sense of sight and hearing collaborate with a body challenged significantly by vestibular difficulties.

What is it like to exist in the world like that? Balance is talked about as a thing to be ‘found’, but it is not simply found. It must be adjusted to the surroundings, from a safe base. It requires extra energy, physically as well as psychologically, for a person with Usher Syndrome to find balance.

A boy once told me how he felt when playing a ball game: “Sometimes my foot slides and I must put it into place again, and while I do that I can’t really see anything.” The boy expresses quite clearly that he loses focus on the thing he is doing, when his balance fails, and he might even lose the ability to use his other senses optimally. I often wonder how many times during a day people with Usher Syndrome experience that?

Children with Usher Syndrome use a lot of energy every day because their senses work overtime, and sometimes their energy runs out, and they are worn out with fatigue or reacts with tantrums.

The following is a story about what happens when people face situations in which they lose

orientation, overview and the ability to act.

Passable landscapes

On a winter’s day a few years ago, I visited a friend who lives in a cottage a little distance from the main road. It began snowing heavily, and when I was driving home, I got stuck in the snow after about 800 meters.

Time was dragging away, and I experienced a number of emotional states during the time I sat there. How might this day end? I tried clearing away the snow in front of the car. I sat totally still in despair, and I tried to find strategies that would get me out of there.

As time went by more cars came, and after some time, which felt like an eternity, a local resident called the local authorities. They sent a vehicle to clear the way and guide us to the main road.

Now, who was I, sitting there, stuck in the snow?

- Someone with anxiety, who did not know how it would all end (a psychiatric case)?
- Someone shoveling snow, fighting for her life (reacting)?
- Someone who despaired (a victim)?
- Someone competent, with thoughts and emotions, waiting to be guided into a passable landscape?
- Someone like everyone else, but stuck in a difficult situation?

I believe that I experienced all of the above during the hour and a half I sat there.

Let us imagine that deafblindness is a condition that

puts itself between the person with Usher Syndrome and the world, or between his/her relations to others, similar to the snow between me and the main road, when the snow was falling heavily.

Let us assume that the child’s reactions such as being afraid, having a tantrum or as a victim are not psychiatric disorders but reactions to the deaf-blindness.

Let us for a moment lean against the hypothesis that people with Usher Syndrome fundamentally are human beings who need support to travel in passable landscapes.

In the following, I will describe the difficulties we typically observe in the child with Usher syndrome type 1, and what kind of support the child between 0 and 18 years of age needs.

The small child with Usher Syndrome

When a child is born with Usher Syndrome it is my experience that you soon observe a child who has difficulties with eye contact. You see a child whose eyes roll a little in their sockets and who has difficulties focusing. This is particularly apparent when the child is in your arms and you move in different directions.

At this point the child is already challenged by the vestibular difficulties which mean that it takes longer for the child to understand the world, especially when it is moving. Therefore the child seems to prefer to lie still and contemplate the world in its first year of life. From birth the child appears to have a hypo-toned or lax body. It is difficult to determine whether the child is born that way, or if it is the vestibular complications that causes the muscle strength to not develop properly.

Being a parent to a child with Usher Syndrome is difficult. The parents intuitively understand that

the child prefers to lie still, but they know that the child needs to move in order to develop his/her motor function, and connect the first impressions of the world in order for the world to make sense. It will also be of concern for parents and professionals that eye contact is not very good.

The child with Usher Syndrome often sits up late, and stands and walks even later. When sitting, the child will often choose a broad supporting surface, for example with his/her legs in a W-shape or with widely spread legs. When the child is tired it often leans forward in sitting position, placing his/her upper body and head on the floor, supported by the chin to still be able to see what is going on in front of him/her.

Moreover, experience from practice shows that children with Usher Syndrome typically begin to walk when they are between 1 ½ and 4 ½ years old. According to Jesper Dammeyer the average age when children with Usher Syndrome take their first steps is 24 months.

In Dammeyer's study, four out of the 26 children examined for Usher Syndrome do not have difficulties with the vestibular sense. Children with Usher Syndrome type 1 will often retain a very wide-based gait.

Gait as well as running often looks very insecure, until the child reaches school age, and maybe even further.

When the child shifts from lying down to sitting, or from standing to walking, it has to use time and energy in order to understand the world from the new position. And as the child uses a lot of energy to compensate for the loss of senses and motor function, we often observe that other functions such as language acquisition are delayed, and the development of the language is often slower than in other children with CI.

Dammeyer suggests that the

combination of reduced sight, reduced hearing and delayed motor development is one of the barriers in relation to developing language and social competences. In Dammeyer's study, eleven out of twenty six children with Usher Syndrome (type 1 and 2) appeared to have delayed language development. The extent of the delay is significantly linked to the level of deafblindness in the study.

Most children with Usher syndrome will have integrated their understanding of body and surroundings with sight and hearing during the age of five to six years, and subsequently language begins to develop extremely fast. Some children manage to acquire language appropriate to their age before they start school at about six, while others do not have enough time between learning to walk and becoming cognitively ready to attend school.

Case: Rachel

Rachel is born with Usher Syndrome. Because she has an older sister with Usher Syndrome, it was detected early. The first year she lies a lot and looks around, but because of her older siblings her motor function is challenged. She is able to sit up at the age of 11 months.

When she is sitting, her eyes roll a lot, and when she loses her balance she does not seem to have normal fall reflexes and falls. She quickly learns to sit with her legs widely spread and falls forward with her chin on the floor. From there she either rolls over to her stomach or her back, to fight her way back up to a sitting position. She is not very keen on lying on her back, because it is not sufficiently strong for her to be able to lift her head for a longer period of time.

Rachel learns to crawl late and

stands up late. She takes her first steps without support when she is about three years old. Shortly after her CI-operation, when she was about one, she began intensive speech therapy a few times a week. The therapy continues until she starts school. Until she is about five, her language development proceeds very slowly and is not age-appropriate.

“Most children with Usher syndrome will have integrated their understanding of body and surroundings with sight and hearing during the age of five to six years”

Nevertheless her language development speeds up at the age of five to six, and her language develops twice as fast as other children at that age with CI. She starts school with a year's delay, and at that time her language is age-appropriate. The fact that Rachel suddenly develops her language so fast suggests that the language delay was due to the complex multiple reduced sense functions and not to cognitive barriers.

Intervention for children with Usher Syndrome from the age of 0-7 years

Rachel's progress is rather normal for most children with Usher Syndrome and CI. However, as mentioned earlier, some children have not got enough time to develop from when they start to walk until they should be ready to go to school at age six. For other

children, knowledge about Usher Syndrome in their surroundings has been scarce, and therefore focus has been on the things they were unable to do. Some children with Usher Syndrome have been assessed for learning disability, autism or other disorders prior to school.

Some are provided with a diagnosis, which may result in them being placed in a special school which does not specialize in CI and hearing impairment, but in learning disability or autism. If this is the case the child may no longer be expected to develop typically and catch up with the delay when the senses have learned to function together. Without specialized knowledge about Usher Syndrome there is a risk that many resign themselves believing that the child will not be able to learn that much. Parents and professionals thus need detailed knowledge about the early development in the child with Usher Syndrome and exhaustive knowledge about integration of senses and an understanding of the child's motor development.

Supporting the child's development the first seven years is about understanding the complex situation the child faces and understanding the child's different ways of behaving and the child's need for extra time and support for development. The child needs to be seen, understood and guided into landscapes which are passable for at small child with motor and language difficulties.

The school child with Usher Syndrome

For many children with Usher Syndrome, the age from seven to 10 years is a good and stable period of their lives. They have a fair grip of their motor function and their language develops steadily. When I have asked people

with Usher Syndrome when they have had a really good spell in their lives they almost always refer to places and situations from the time when they were about seven to ten years old.

Between 10 and 14 the problems with sight may become more pronounced, and the child once again has to reorganize his/her senses and body in relation to the surrounding world. The child becomes more reflective and needs age-appropriate explanations as to why he/she sometimes does not feel like other children and why he/she is not capable of doing quite the same things as other children.

It is thus important to externalize the deafblindness and make the child understand that it is a condition in the child's life which may put a barrier between the child and the world, or between the child and the relations he/she wants to be part of. The deafblindness is experienced differently in different situations.

Communication may not be an issue when the child is sitting with a friend in a place with good lighting. However in a dark school yard on a winter morning, the disorder may cause the child to need support to communicate and find his/her way back into class. The child therefore develops various strategies in order to be able to live in the chaos he/she faces.

For some children this means that they develop anxiety and psychiatric symptoms, act or react with tantrums, or become quiet, gloomy or introverted. Quiet and introverted children may turn the problems against themselves or become victims of bullying.

At this age the child often experiences a change in their social life with other children. Playing switches to talking, and it gets harder to divide ones attention between playing, a

computer game, and being a part of the social communication at the same time. The child begins to understand the consequences of his or her disability, which may cause worrying, sorrow and sometimes symptoms of depression.

Case: Hannah

Hannah was born deaf and received a CI when she was about one year old. Hannah's spoken language developed fairly quickly. She is very active and loves playing ball and other physical activities.

However, when she started school her language development was not age-appropriate, resulting in her being referred to a special school for children with hearing impairment. At school they were uncertain about her skills and her language development, mainly because she did not speak much. Yet, in a network for children with sight and hearing difficulties, she spoke a lot. At the age of ten she became very introverted and seemed worryingly sad. She sometimes reacted angrily and violently. She lashed out at other children and threw large objects, like computers and chairs.

At the age of 12 she was referred to a psychiatric ward for children assessed for ADHD or autism.

Hannah had none of these conditions, but signs of depression were found, suggesting that her violent outbursts were caused by her own insistence as being a clever girl. The cause of her behavior was the chaos she experienced as a consequence of Usher Syndrome. This is rather common.

Intervention for children with Usher Syndrome between 7 and 14

Parents and professionals are responsible for guiding children from this age group into passable

landscapes; providing them with the support they need in order to prevent chaotic situations happening and to develop into competent and problem solving human beings.

The child must learn to understand and express his/her thoughts and feelings, including when situations are difficult. It is crucial to support the child in building good self-esteem and not try to shield the child from the pain caused by knowing his/her situation.

It is recommended that the child participate in types of physical activity where he/she can excel. A strong body can compensate for vestibular difficulties and for possible obesity, tensions and stiffness caused by reduced functions of the body. Ball play rarely works with this age group, while outdoor life, tandem biking, climbing, riding, swimming and yoga are better suited.

During the early years of school the child must learn to use such assistive technology as lamps for the visually impaired, optics for the visually impaired, and tele-loop. It may also be necessary to introduce sighted guide techniques.

Young people with Usher Syndrome

When the young person is about 14 to 15 years old it is important to consider his/her future opportunities. What does the young person want for him/herself? It can be difficult to want something if you do not understand your situation; everything is chaotic, and you only see limitations. Therefore, conversations and sincere explanations are crucial. It is important to be both realistic; but not to be limited by what you think is possible or impossible. It may be possible. We know people with Usher Syndrome who are

highly educated, have started a family, have travelled around the world and have performed extreme athletic feats.

It is important for the young person to be in the company of other young people, who are in a similar situation. The young person needs to learn how to express their needs.

Is it still possible for young people in this age group, who are unhappy, to be guided into passable landscapes? Is it possible to reverse a development which is ruining the young person's self-esteem and prospects for the future? I will now tell you about Kevin, who succeeded in doing just so.

Case: Kevin

I met Kevin at a school for deaf children in Tallinn, Estonia. He was 16 years old and the only one with Usher Syndrome at the school. I participated in a meeting with his teachers and his mother, where they told me that Kevin had Usher Syndrome, but that this was not his biggest problem. "What is Kevin's biggest problem?" I asked.

The answers were varied: "He's not social"; "he doesn't understand what's going on in lectures"; "he doesn't want to learn"; "he spends too much time at home with his mother"; "he has difficulties concentrating"; "he is immature"; "maybe he's autistic"; "he doesn't understand what Usher Syndrome is", etc.

Then I met Kevin. He was a kind and polite young man who would not talk about his disability. He attended a class where I was pleased to find that the lighting was good; he was in the right place in terms of being able to see both his teachers and the blackboard. Nevertheless, I could tell how much it challenged him when the teaching took place as a discussion between the teacher

“We know people with Usher Syndrome who are highly educated, have started a family, have travelled around the world and have performed extreme athletic feats”

and the students. He could not see what they said.

At my next visit to the school I invited Kevin to a meeting with his primary teacher, his mother, a sign language interpreter and an Estonian interpreter. I explained to Kevin that I would like to show everyone how this disease affects his vision and asked if he would help me.

In the beginning he sat a bit away from the table, a bit sullen, only cutting in to say when something did not apply to him. However, he soon took over the meeting and explained how he could see right ahead but not peripherally, and how his sight was functioning in the dark, and how difficult it was for him.

He told us that the teachers sometimes asked him to do things he could not do because of his visual impairment, and he explained that the eye specialist had told him that it would get worse. He reflected on what he might do as an adult and reasoned that he, at any rate, would be able to put products on the shelves in the supermarket. At the end of the meeting he asked whether he could borrow my materials, because he wanted to tell his classmates and other teachers about his visual impairment. Of course this was no problem, and then Kevin slumped on the table

after his enormous effort. When I looked at his mother she looked at him proudly, with tears in her eyes.

When I visited the school one last time, Kevin had given a little talk for his classmates. I had another meeting with Kevin's mother and teachers, and now everybody agreed that Kevin's problems were due to Usher Syndrome.

Kevin told me he had met two grown up men with Usher Syndrome. He had been provided with a mobile phone, so he was able to contact his mother, if he got into trouble when he went out with his friends.

Kevin's story could just as well have taken place in Denmark.

Intervention for children and young people with Usher Syndrome between 14 and 18

When the young person with Usher Syndrome is between 14 and 18 it is important to equip him/her with the ability to find the way into passable landscapes in life; help him/her to develop an extended understanding of his/her disability, developing an understanding of the syndrome and the interplay between the senses and the body.

It is also important that the young person is supported in understanding the significance of using assistive technology when necessary. The young person must be introduced to new technology to create a worldwide network.

It may be useful for a future career, when you have such a rare disability.

In addition to this, the young person must also learn to understand the essence of energy loss, know his or her strengths and the limitations inherent in the disability. The young person must learn to know and manage symptoms of stress. The young person should know the consequences if he/she does not stay in shape or is physically active.

Parents and professionals can support the young person to stay in shape in order to compensate for the losses of senses and the dysfunctions of the body. Finally the young person must have support to find and participate in relevant networks.

Summary

People with Usher Syndrome have difficulties integrating their senses and body in relation to each other, their relations and the world around them. They experience these difficulties every day, every minute, all through life, and it influences their possibilities to participate in relations and take part in society around them. Since these individuals seem to constantly face difficult situations, they need support and self knowledge to be able to revert to passable contexts.

People with Usher Syndrome need to understand their

difficulties in the light of their multiple loss of senses, including balance and vestibular difficulties, shifting and progressing difficulties with sight, reduced hearing and the use of CI and other assistive technology. They need to understand what it is like to experience extreme losses of energy because of the sensory overload.

They need to learn strategies to be able to move forward in spite of these barriers. They need to understand themselves in the light of the many, long and dire struggles they will face during their life; including understanding what they will miss out on, when everything demands their time and energy.

It is crucial that parents and professionals are there to support and help people with Usher Syndrome their whole life. It is important that people around the person with Usher Syndrome understand, or try to understand that deafblindness is a circumstance that changes in the different situations in life. They need people around them who can communicate this in a problem solving and productive manner.

Deaf-blindness is in itself not part of the person, but a circumstance which stands between the person, his/her relations and the surrounding world – exactly like the snow that fell between me and the rest of the world.

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¹ Behavioral and Brain Functions is an open access, peer-reviewed, online journal that encompasses all aspects of neurobiology where the unifying theme is behavior or behavioral dysfunction. www.behavioralandbrainfunctions.com

Cognitive assessment of people with congenital deafblindness

October 22–24, 2013 in Dronninglund, Denmark

For five years, the Nordic network on cognitive assessment of people with congenital deafblindness has been working on developing guidelines for assessment. One aim of the seminar is to provide network partners with the opportunity to discuss and reflect on this work. An additional aim is to create cooperation among Nordic and international experts working on cognition in people with deafblindness.

This will be a working seminar with time for reflection and discussion as the focal point. There will also be presentations on relevant issues in relation to assessment work.

The seminar will be in English.

Target group

People who are responsible for, and engaged in, assessment-related work for people with deafblindness. By "assessment", we here refer to both identifying development potential in connection with planning of intervention and evaluating a person's development at any given time and compare this to other persons – or the same person at another time – and in this way "measure" the development.

Content

Presentation of the network's ideas and thoughts on cognitive assessment of people with congenital deafblindness.

Topics will include:

- Tactile cognition
- Tactile working memory
- The executive function scale
- Using general assessments and adapting them to people with deafblindness
- Using the developmental profile

Seminar management

Hans Erik Frölander
Psychologist and Ph.D. student, Sweden

Flemming Ask Larsen
Semiotician and Ph.D. student, Denmark

The seminar starts with lunch at 12:00 on October 22 and ends with lunch at 12:00 on October 24

Location

The seminar will be held at the beautiful **Dronninglund Castle**, center of Nordic staff training for more than 30 years. Address: Slotsgade 8 • 9330 Dronninglund • Denmark

Seminar Fee

DKK 3250,- / €435,- including meals and accommodation.

Applications must be registered by September 9, 2013 at www.nordicwelfare.org/cognition2013

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Acquired Deafblind Network (ADBN)

Liz Duncan reports:

With the conference in Lund Sweden, now a memory, the coordinating group and the new local planning team are now hard at work on the next Conference planned for Belfast Northern Ireland, November 2014.

The coordinating group met back in February to evaluate the Swedish conference and begin planning the Belfast conference.

As always, the evaluation from delegates was extremely useful (a big thank you to everyone who took the time to give us their views and comments) and as a result, we have made some changes to the format of the programme for Belfast.

We also have our theme for the conference, 'Life, Love and Laughter' which was suggested by one of the delegates in Sweden. The coordinating group felt that the theme offered the opportunity for some new and hopefully innovative plenaries, workshops and ways of sharing our experiences.

Some of you may have used the ADbN website in the past. This has now closed and the content will be moving over to the Dbl website soon. This will make it easier for people to access the network and will also mean that it's much easier for people to network with each other, right across the world. If you have any comments about this, or suggestions for new content, then please do get in touch with me.



And in August, there will be the Dbl European Conference in Lille, France. ADbN will be running a network event during the Conference, which promises lots of thought-provoking discussions, so if you are attending the Conference, please do come and join us.

Liz Duncan

Email: Liz.Duncan@sense.org.uk

Deafblind International (Dbi) preconference on



CHARGE Syndrome

August 24 2013
Lille France



The preconference from the Dbi CHARGE Network (www.dbicharge.org) will be held on **August 24, 2013** in advance of the 8th Dbi European Conference in Lille/France, at the Ibis **Hotel Lille**

Centre Gares (29 avenue Charles Saint-Venant, 59000 Lille, France)

(a ten minute walk from the Grand Palais, location of the main conference).

There will be two main topics we are going to present, reflect and discuss in depth:

Social-Emotional Skills and Communication

No	Time	Programme
1	08:30-9:00	Coming together and enjoying the exhibition of photos!
2	9:00-10:30	SOCIAL-EMOTIONAL SKILLS – presentations (speaker 1: Sonja Friberg, speaker 2: Gail Deuce)
3	10:30-11:00	Morning coffee break: Time for sharing
4	11:00-12:30	SOCIAL-EMOTIONAL SKILLS – discussion and feedback (facilitators: Sonja Friberg, Gail Deuce, Andrea Wanka)
5	12:30-13:15	Lunch
6	13:15-14:45	COMMUNICATION – presentations (speaker 1: Steve Rose, speaker 2: Andrea Wanka)
7	14:45-15:30	Afternoon coffee break and time for registration
8	15:30-17:00	COMMUNICATION – discussion and feedback (facilitators: Steve Rose, Andrea Wanka, Odette Haubrich)



Dr. Andrea Wanka

In addition to the program we plan to have three **interactive walls**, where the attending people can collect and share ideas. One will be a collection of **important topics** to be discussed in the forum on the website of the Dbi CHARGE Network (www.dbicharge.org). One on **personal reflection** of your work in the

field of CHARGE Syndrome, and one **white wall**, open for every idea which comes up during this intensive day of sharing knowledge, ideas and questions.

In addition to the walls there will be a small **exhibition of photos** taken of children, youths and young adults with CHARGE Syndrome by the German photographer Robert Bühler (www.robertbuehler.com).

The preconference **cost is €75** which includes the venue, two coffee breaks and lunch.

The conference application form can be downloaded from <http://www.dbilille2013.eu/> and send to Gail. Deuce@sense.org.uk

CHARGE Network Meeting Announced:

On Wednesday August 28th from 9 until 11:45 during the Lille Conference, the Network will host an open discussion Network group meeting. Everyone is welcome.

In addition to topics that might be suggested during the preconference, Network members or others can send topics for discussion to **Andrea-Wanka@dbicharge.org**



European Deafblind Network (EDbN) Ricard Lopez reports:

Recently EDbN has celebrated two important successes. The first one was the constitution of the European

Platform of Deafness, Hard of Hearing and Deafblindness. The Memorandum of Understanding (MOU) was signed in Copenhagen, on the 26th of May 2012 during the General Assembly of the European Disability Forum (EDF).

The platform, which represents 80 million Europeans, has been formed to enhance, strengthen, and cultivate a robust and enduring collaboration between the 5 most important European NGOs working on Deafness and Deafblindness: the European Cochlear Implant Users (EURO-CIU), the European Deafblind Network (EDbN), the European Federation of Hard of Hearing People (EFHOH), the European Federation of Parents of Hearing Impaired Children (FEPEDA), and the European Union of the Deaf (EUD), for the express purpose of benefiting Deaf people (including Sign Language users), Hard of Hearing people, Deafened people, and Deafblind people and

their families regardless of the language, the communication system or the assistive technologies they use (hearing aids and cochlear implants). We aim to strengthen the EU 2020 strategy and the EU Disability Strategy with regard to full and equal participation in society. The first activity of the platform consisted of a conference in Brussels; you can read a summary of it in this magazine.

A second success is the project European Deafblind Indicators (www.deafblindindicators.eu). This project aims at creating a Common European Framework for the assessment of institutional models of care for deafblind people based on indicators created ex novo: the Indicators of Deafblindness Equality in Europe (IDBEE). Its importance lies in the fact that great differences in the degree of attention exist among the various European States. The data collection through these indicators, including the various partial publications that have been issued by some organisations, should enable the detection of best practices on a European level and recommendations on the design of models of care in this field.

This Partnership seeks to bring together 14 of the



Marcel Bobeldijk, EFHOH President; Ricard Lopez, EDbN President; Yannis Vardakastanis, EDF President; Yannis Yallouros, EUD Vice President; Sari Paloposki, FEPEDA Vice President; Gilles Cognat, EURO-CIU President and Teresa Amat EURO-CIU Vice President.

most important organisations working for deafblindness in Europe. The 13 participating European States (Spain, United Kingdom, Denmark, France, Portugal, Romania, Hungary, HR, Netherlands, Lithuania, Austria, Finland and Slovakia) represent the majority of the most advanced countries in the world that treat people with deafblindness.

Presently we are setting up a new project within the Comenius-Regio Partnership program of the European Union with the aim of reinforcing specifically the good practices in the educative stage (up until 16 years old) and also the European Deafblind Indicators project, making possible the publication of the book with the conclusions and results.

Regarding the European Disability Forum (EDF), as EdbN we are part of different groups of experts: Structural Funds, New Technologies, New Accessibility Law, etc.

“We aim to strengthen the EU 2020 strategy and the EU Disability Strategy with regard to full and equal participation in society”

Due to the fact that these topics may cast a great influence on future policies in the European Union we ask all EdbN member organisations to consider identifying some expert professionals on these topics in order to work towards a common position taking

advantage of the excellent synergies we have developed with EDF during the last years.

Finally, regarding the 8th DbI European Conference in Lille, EdbN wishes to assume an important role organising a pre-conference activity on the Saturday 24th of August

and presenting an official talk about the European Deafblind Indicators project. Please, keep an eye to this via the EdbN website www.edbn.org.

It is a good time for the organisations that are still not part of EdbN to ask to be members.

Mind the Data Gap! Lack of statistics for an effective EU inclusion strategy?!

The very first activity carried out by the European Platform of Deafness, Hard of Hearing and Deafblindness has been the organization of a conference on the 15th of November 2012 in Brussels with the following headline: Mind the Data Gap! Lack of Statistics for an effective EU inclusion strategy?!

The aim was to explain to the European Institutions the difficulties that exist trying to find high quality statistical data on specific hearing disabilities and the problems that arise from that, especially when it comes to policy-making.

In their welcome speeches, Ádám Kósa, president of the Disability Intergroup in the European Parliament, and Yannis Vardakastanis, president of the European Disability Forum, highlighted the importance of projects like this Platform, a united voice for all people with hearing disabilities.

Lucy Drescher, from EdbN, called for quantitative and qualitative data about specific disabilities. The Platform would like to see questions about disabilities



Representatives of the platform and some of the speakers and guests.

included in the national censuses of the Member States of the European Union and also in relevant European surveys. Asking the right questions is the key to getting useful statistics.

"If you combine the different data of our organizations, there are 80 million people with a hearing disability of some kind in Europe", stated Mark Wheatley, from EUD. This is roughly equal to the population of Germany.

The Eurostat Representative, Bart de Norre, explained the different statistical studies that are carried out about social aspects of people's lives and the financial difficulties to have these kind of questions asked through Eurostat.

Organisations such as the

Platform are not the usual sources of experts for these institutions "It is very rare to have direct contact with platforms like yours. Almost all experts consulted come from national agencies or the European Commission DG Justice, not disabled people or their representatives of NGOs." Unofficial EC sources claimed.

"People with disabilities are one of the most vulnerable parts of the working force, they are often unskilled, because they have three times fewer opportunities to continue learning and training themselves" stated Lázlo Gábor Lovász, member of the United Nations Committee on the Rights of Persons with Disabilities.

Stephanos Grammenos, member of the Academic Network of European Disability Experts, indicated that: "8% of European Citizens state that they are disabled; 5% receive some kind of financial help. Furthermore, 37% of people with disabilities are in risk of poverty. This can be compared to the 22% of people without disabilities who are in the same risk."

The Platform would like to encourage the European Commission to work towards harmonisation of the 27 Member States on the issues of statistics on disability.

The conference had as guests representatives of the five most important European political groups, Commission Officers and representatives of other

important European Institutions.

The European Platform of Deafness, Hard of Hearing and Deafblindness is a Young Alliance between five European NGO's dedicated to the whole collective of people with Hearing Disabilities coming from very different perspectives. (European

Association of Cochlear Implant Users, European Deafblind Network, European Federation of Hard of Hearing, European Federation of Parents of Hearing Impaired Children, European Union of the Deaf).

Ricard Lopez
rlopez@edbn.org

Kick-off meeting in Glasgow of the Project "European Deafblind Indicators"

The experts in deafblindness from around Europe, who held their first meeting in Glasgow on the 19th and 20th of November 2012, started off this two-year project granted by the Grundtvig Programme of the European Commission. The meeting joined the nine official organisations of the project, coming from eight EU Member States (United Kingdom contributes two organisations), gracefully hosted by Sense Scotland in Glasgow, placing their facilities at the disposal of the 25 participants, who had the chance to visit their centres and services.

In an amiable atmosphere, the different project tasks were assigned to the attending organisations, including the workgroups regarding the Deafblindness domains that need to be worked on. The domains that have been established are the following: disability rate/demographics, personal and family life, choice and control, access to goods and services, education



Official photo of the "DeafblindIndicators.EU" kick-off Meeting in Glasgow.

and lifelong learning, work and employment, and last but not least, incomes and poverty. Other working groups were approved as for instance; Standards for services; Generation of statistics and comparative graphics and Contact group for non-official and new entities.

During the seminar, the concept of "European Deafblind Indicators" was also approved as the main defining concept of the project, which will also be used to name both the website (www.deafblindindicators.eu) and the final book, which will include the concluding data collected during the two years of investigation. It was agreed that the results will be presented at a hearing

in the European Parliament and in a final seminar in Barcelona. Both events to be held in 2014.

The presence of the most notable organisations within the field of deafblindness in their respective countries will guarantee the quality of the results; nevertheless, the members agreed on an enlargement policy to keep the organisations from the five European countries that did not receive funding within the project, as well as other European countries wishing to join this challenging enterprise.

If you or your organization are interested in being part of this project please let me know rlopez@edbn.org

Some interesting Information:

www.edbn.org EDbN website

www.deafblindindicators.eu

Project website

www.deafblindindicators.eu/index.php/aboutus Partners of the Project

Ricard Lopez
rlopez@edbn.org

Social-Haptic Communication Network

Riitta Lahtinen and Russ Palmer report:

The Social-Haptic Network is collaborating with the "Signo" organization in Norway. After a one-day professional meeting and teaching day, Signo organised a six-day social-haptic communication course during 2013. The tailor made programme for the professionals working at Signo was developed according to three levels: Basic, Intermediate and Advanced. These different levels included basic concepts on social-haptics and haptemes (grammar), which allow the opportunity to exchange ideas and practical tips on how to apply haptics (touch messages onto the body) with different client groups. During the learning process the students are able to discuss with the teachers specific related issues in applying these methods through skype or email.

Co-operation with Royal Association for the Deaf in the UK and Royal Dutch Kentalis in The Netherlands gave the opportunity for the professionals, interpreters, deafblind people and family members to work together in a one day workshop to discuss and share experiences on how social-haptic communication can be used in everyday life.

The Finnish National Board of Education has

accepted the Instructor of Haptics skills level course as a part of the Special Vocational Qualification instructor's curriculum of Visual Impairment skills at Keskuspuisto Vocational College Helsinki in Finland. Other special instructor areas include educational disciplines from low vision and mobility training, IT and Braille for the blind. This pilot research project course was started in January 2013 and sets the standards for the process to learn and use haptics with blind and deafblind people.

KELA, the Social insurance institution in Finland (Governmental Social Services Department), has recognised haptics as an official communication system for deafblind, visually and hearing impaired people.

Trainee students and qualified Sign Language Interpreters who wish to specialise working with deafblind people, now have the opportunity to do extra studies of 3 credit points (78 hours work) courses on



social-haptics.

Research and development projects with Turku and Helsinki Universities and professionals are continuing during 2013 in the areas of musical haptics. Helsinki University is focusing on the area of haptics and multi-perceptual learning.

The second Social-Haptic Communication Network meeting is taking place during the International Accessibility and Multimodality in Communication symposium at Turku University.

More information and subject related abstracts can be found on the website (<http://tucs.fi/conferences/acmuc2013/>)

“During the learning process the students are able to discuss with the teachers specific related issues in applying these methods through skype or email”

Tactile Communication Network

Bernadette Van Den Tillaart reports:



“We appreciated the opportunity to share with and learn from so many colleagues across the United States”

Network, younger participants (everybody under retirement age!) became interested in Deafblind International as well.

In addition, we presented a 2-day training seminar with the TSBVI school and outreach program teams, involving video examples of their students. This connected the conference information and discussions directly with the students they were familiar with.

We appreciated the opportunity to share with and learn from so many colleagues across the United States. People asked us how they could participate in this group. Like the other networks, each or every other year the Tactile Communication Group has had activities to share findings and ideas, with colleagues at different places in the world. This has led to initiatives amongst people, changes in perspective, and connections with our group. Their ideas and findings support our work, and we try to give back to the wider deafblind community through those activities and by providing access to the movie and companion guide.

This question of network participation is important. Being part of such a global organization as Dbl, focusing on a relatively small population, how can Dbl networks be true networks? Or maybe the question should be turned around. What do we mean by a ‘network’? Does it mean providing physical meetings beyond the conferences? Does a network share digital information?

Does a network include activities such as performed by the Tactile Communication Group? Most networks have a small core group. If a network would want to welcome many members, what can they offer? What do we mean when we say: a network member? Does a network member need to register; but then, what does that provide differently than the open access to resources from the webpage? What can be expected of a network with the current website possibilities? How can we connect with colleagues in the field, beyond our own ‘local’ (travel) circle? We welcome ideas regarding this discussion.

The Tactile Communication Group will present at the Dbl European Conference Network Day in Lille. This will include the sharing of the film ‘Landscape of Touch’. The Tactile Communication Group and the Communication Group will join forces during the morning of the Network Day.

We are in the process of updating our webpage. We will provide information on how to order the film. We also will share with the webpage visitors other resources related to tactile communication.

To find information about ordering the DVD ‘Landscape of Touch’, go to the website of Deafblind International, click on Networks and click on Tactile Communication Network. http://www.deafblindinternational.org/network_tcwg.html

Over the years, the Tactile Communication Group has had many network opportunities, in different continents and with different organizations.

This past February we were invited by the Deafblind Project from the Texas School for the Blind and Visually Impaired (TSBVI) and Texas Tech University to speak at the ‘2013 Texas Deafblind Symposium’ in the United States. 300 participants, from inside and outside the state of Texas, attended both the presentations at the opening and last day of the conference. Many participated in the lively and involved discussion about experiencing the world from a tactual perspective and its impact on communication.

Many parents (approximately 80) were among the audience and their examples and ideas supported the presentation through sharing. The Daley family showed in their own presentation why the children with deafblindness need tactile communication and tactile access; making the case for intervenors.

Some of the participants started work during the rubella epidemic period and are current members of Dbl. Because we presented as the Dbl Tactile Communication

Proposal for a Deafblind Youth Network

Proposals for a new youth network have recently been submitted to the Dbl management committee. The network aims to provide a collective international platform from which young Deafblind people will inspire others, share views, develop ideas and influence policy makers. There will also be a strong emphasis on developing and sustaining friendships through participation in a range of engaging and fulfilling international activities. This will promote and value the positive contribution that young Deafblind people make in their communities and respective countries.

The proposed network identifies that youth transitioning from childhood to adulthood are entering a very important stage of life. Membership of this network would provide opportunities to nurture Deafblind young people to express their aspirations and goals for the future. A young person with the developed confidence and ability to represent themselves and others at an international level will be a huge asset to their respective Deafblind organization.

Initially the proposed network would bring together potential members through social media including forums and discussion groups. This will gauge interest in the network and enable active input of each potential member.

Responsibilities within the network would be allocated among the young people ensuring a sense of ownership among members. The planning of future activities would be in response to the suggestions of the young people. These may include exchange visits, network holidays and participation in Deafblind International conferences.

Deafblind Youth Network is the shared idea of Alan Avis and Simon Allison, both of whom are experienced in youth work through their roles within Sense. Simon explains the inspiration behind the new network,

"The network will be built around creating fun experiences that celebrate and champion young deafblind people throughout the world. We want to unite the next generation of young deafblind people supporting them to protect their civil rights

and maximize the equalization of opportunities in all aspects of life".

The proposals for the new network have already been shared with some young Deafblind people. The responses clearly demonstrate both the enthusiasm and a need for such a group.

"I am very interested in the idea of a network for young Deafblind people. It would give me the fantastic opportunity to learn about new cultures and make friends with other Deafblind young people worldwide"

Snædís Rán Hjartardóttir
(Iceland)

"I would really like to participate in the Deafblind Youth Network.

I have a strong interest and desire for international work. I love the feeling of inspiring others in foreign countries outside of the USA to have hope and strength".
Corrina Veesart (California)

For further information on how you can become involved in supporting the new Deafblind youth network please contact alan.avis@sense.org.uk or simon.allison@sense.org.uk

Correction

From Dawn M. Guthrie, PhD
Associate Professor
Dept. of Kinesiology and Physical Education, Laurier University.

Dear Stan,

I am enclosing **the attached statement** to update and correct my article that was **published in the Jan 2013 edition of Dbl Review (pages 66-67)**.

"At the time of publication, Project 3 was finished (completed in June 2010) and further pilot testing of the instrument was conducted with 135 clients as well as one-on-one interviews with 8 clients and 6 parents.

The article also incorrectly stated that the Ministry of Community and Social Services (MCSS) was moving ahead with implementation of this assessment tool. MCSS has not finalized an assessment process or funding model for adults who are deafblind".

The Napoleon's Code... in Europe¹!

...or the medical, societal and psychological situation for elderly with
acquired hearing and vision loss



Christine
Aktouche

In France, we are still registered through the Napoleon's Code, which in 1804 unified the entire country under the same civil laws with the same rules for all the French population from birth to death.

Since, then of course most of the laws have been modified in relation with the evolution of our population's way of life. However, regarding the elderly throughout Europe, when they lose their autonomy through sensory disabilities, they look on themselves as they were looked upon in the 1960's as people not useful to society.

We are now trying to understand why this growing elderly group with dual sensory impairment (DSI) is not recognized as a distinct population group in France or even in Sweden and the Netherlands, countries well-known for their 'avant-garde' social welfare programs. Is Napoleon's ghost still wandering in Europe as an expanding cloud creating a European partially sighted and partially deaf population in spite of new knowledge in medical research?

Medical situations observed with elderly DSI

As a matter of fact, recent research from the Pasteur Institute² focussing on 'genes, perception and cognition' indicated that our brain never stops producing new neurons. This is done mainly in two locations - the olfactory and spatial memory structures. This recently understood human cerebral plasticity is not dependant upon the level of our knowledge, education or professional responsibilities but instead through our capacity to discover and understand new things.

For example, during visual re-education and stimulation activities, the patient uses his brain plasticity to reorganise new retinal fixation areas, new ocular motor pathways and new eye movement activities. Having accomplished that, he becomes able to use optical aids to read (and even write) through these new cerebral automatic responses; even to understand the meaning what he is reading.

So the elderly are still able to use and train their attention, memory and new visual capacities at any age, for any visual competency

or visual acuity. However, these treatments are most of the time the only ones for AMD (Age related Macular Degeneration), retinite and hemianoptia³ because of the lack of other medical or surgical solutions.

Through my own experience, I have, for many years, noticed that most ophthalmologists in France fail to prescribe these low vision rehabilitation programmes as systematic treatments. Two main reasons could explain this failure:

- The first one could be explained by the fact that neuro-vision competencies do not belong to the eye but to the brain; suggesting another specialist is required.
- The second one is the fact that a patient becoming old with DSI endures this condition in silence and often in secret. Gradually, as the sensory loss increases, this patient takes on a more depressive attitude. Consequently, the ophthalmologist tends to judge that the person is unable to assume a visual rehabilitation program because it's too late!

But our study also demonstrates that in Sweden or in The

¹ Paper presented at 8th ADbN Conference in Lund, Sweden, November 7-10, 2012

² www.pasteur.fr

³ Defective vision or blindness in half of the visual field of one or both eyes...from www.wikipedia

Netherlands where visual rehabilitation programmes are quickly available after the ophthalmologist diagnoses AMD, and technical aids are offered through social services, people with DSI continue to resistant to these benefits?

To conclude discussion about these observed medical situations, I strongly recommend two points of advice to improve functional vision for elderly people with dual acquired sensory impairment:

1) Improve their capacity to make adaptations to continually improve themselves throughout their life. This means to regularly practice their cerebral capacity, not just by focussing on past knowledge but always trying to discover and understand new situations through a positive curiosity. Maintaining cerebral plasticity is easy when one's cognitive capacities are in a normal, regular and active way of life. Training is easier for those who receive the bad news if one is still able to think with an open adapting mind.

2) Don't wait too long before too much of the vision is lost. Patients must join a specific program of visual rehabilitation as soon as to train their existing (but deteriorating) visual capacities while they are still able to read, and while they feel they still have enthusiasm to find pleasure in experiencing life. We have to regard this sensory loss as a new and natural change that one has to face, even if professional help is necessary

to cope with these changes.

Psychological, Social and Cultural aspects of elderly DSI

After the partial medical loss we have just observed, let's further look at the psychological, social and cultural impacts if we are to better understand the difficult situation that newly diagnosed people with DSI face.

When life is progressing as normal, with no particular health problems, elderly peoples way of life today can be described as positive, strong and active. They practice various sporting activities, wear fashionable and colourful clothes, travel, attend university and they fight for their recognition within the "cult of youth".

But **why** should a disease, particularly visual deterioration, destroy a person's stable self-image? Why does it become such a nightmare to the point of **weakening their self-esteem**? I suggest three different situations that I encountered in my clinician practice:

a) Vision loss for most European people is synonymous with **fear, darkness and death**. "This is the end mentality! I have lost my autonomy and thinking capacities". These strong negative representations belong to our European 'collective subconscious' related to a past time when blind people were rejected from society and considered 'mentally dangerous and weak'. This negative picture of oneself even worsens with

their personal distress, as they look upon themselves 'as a door they refuse to open'!

b) This negative picture, reinforced through a negative visual prognosis together with the feeling of abandonment by the medical community, leads to a type of psychological **trauma**. I say trauma because the new realization of now having a low vision capacity, unable to rely on their vision, creates a real challenge to be able to think in a new future direction.

Why then is that person in danger of not thinking positively about their life ever again? They are thinking: "How could the youth cult have disappeared from me so quickly?" The reason, at this point in their trauma, is that 'their new fashionable positive elderly life model' has now been replaced by a **weaker inner representation model**. A bad vision of their grandparents, often characterized with blindness and dementia, appears to them.

Developing this new 'ancestral attitude' for the visually impaired elderly person is a very dangerous approach for their own future. Unfortunately, it appears **much easier** when one feels lost and without any more fighting energy, to simply give up and remember the past, than to take an unknown direction. Simply stated, the final life project and philosophical way of life has regressed now to become a passive acceptance of what has happened as the **normal destiny with old age!**

3) After this trauma and psychological consequence, let's look at the **third point** as the social impact of the situation with DSI. I am now talking about the perceived negative image of having to pay for and use various visual and hearing aids to be like 'before'.

I spoke earlier about the cult of youth and the modern characteristics of the senior population. Further to previous discussions when sensory disabilities develop, my question now is whether it is fashionable or not for the 'modern senior' to wear technical aids? Who is proud to show everyone that they are wearing an obvious 'aging device'? Why colour your white hairs if at the same time you need to wear visible, unattractive and often ineffective technical aids? Why do the French population pay a 'fortune' for

such a difficult and personally unsatisfying system?

So, without professional support and advice, some people see more negative points than benefits and develop a bad self-image, forgetting the real advantages of professional and technical support.

Conclusion

To conclude I hope this paper will convince the technical aid industry that the potential 2 to 3 millions of people in Europe with dual sensory impairment is recognized as a real future market opportunity which requires positive publicity. Effective real life positive TV stories about seniors improving their lives through these aids should help convince future clients that the necessity of living with technical aids is a new

European norm.

And as with Napoleon and the French civil code, I hope politicians of the European parliament will support such necessary projects through public health legislation and funding to promote information about these real needs among a rapidly growing population. So satisfied with a continuing good self-image, with effective training in the use of such aids, and purchased at lower prices, dual sensory impaired seniors will look favourably to their future again.

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Editorial *(continued from page 3)*

'Nothing About Us Without Us' is a real working tool to ensure that people who are deafblind have a real 'say' in the implementation of the United Nations Convention on the Rights of Persons with Disabilities.

From a personal perspective, it is exciting to feature a report on the opening of the Resource Centre for Congenital Deafblind Persons by the Ontario Chapter of the Canadian Deafblind Association. This is a dream come true that a Centre of Excellence, developed along the line of similar facilities in the Nordic countries, Scotland and the Netherlands, is now operating in Canada.

Conferences represent a significant feature of the

work of DbI; so as usual, this edition makes a number of announcements about upcoming conferences and workshops. Just weeks following the publication of this edition, the 8th DbI European Conference will be in full swing in Lille, France. Preceding the conference, the CHARGE Network has organized a one day conference on August 24th focussing on Social-Emotional Skills and Communication of children with CHARGE Syndrome. Other conferences in preliminary stages of development are the 10th ADBN Conference, planned for Belfast Ireland in November 2014, and the 16th DbI World Conference planned for Bucharest, Romania in the

last week of May 2015. More will be publicized on these events in future editions.

It seems that each edition of the review would not be complete without a feature article about a DbI related conference. The lead article in this edition is an overview of the very successful 2nd Joint ICEVI-DbI Asian Conference held this past April in Ahmedabad India, hosted by Sense International India and the Blind People's Association. Check out their conference website for more information and conference proceedings.

Happy reading,

Stan Munroe

Using the UK system of vocational training to shape the workforce supporting deafblind people

There are 1.8 million workers in Health and Social Care in the UK. Work carried out by Sense and other organisations in the UK has meant that they can now all access qualifications that help them develop their skills and knowledge about deafblindness. This article explores what we did and asks whether there is value in Dbl members sharing their experiences of vocational training frameworks so that we can learn together.

Introduction

Historically, the UK adult health and social care workforce has never been required to learn about deafblindness as part of their core training. For workers in the field of deafblindness there has been no strategy by the UK workforce regulators to support them in the development of the necessary specialist skills and knowledge.

Sense has worked tirelessly over the last decade to influence workforce development policy makers in order to redress this. The landscape in 2013 is quite different. For the first time, all of those 1.8 million workers have the chance to develop skills and knowledge about deafblindness as part of their vocational training programme.

How did we do it?

It took a long time and many many meetings to persuade policy makers that deafblindness should be recognised in the mix of skills and knowledge social care workers need. We campaigned for about 5 years before we even got as far as getting this recognition. We didn't work alone – we collaborated with a number of other voluntary sector agencies so that our voice was stronger. We had to repeat our messages over and over again before we succeeded in getting recognition. Finally we

managed to get agreement that the new UK vocational framework would include a sensory disability pathway. All we had to do was the work! Sense was commissioned to write materials and they were incorporated into health and social care qualifications from 2012.

What did we develop?

We developed a suite of modules at levels for direct support staff, managers and specialist workers that addressed the main functions carried out by a person working in health and social care supporting someone who was D/deaf, blind or deafblind. These formed part of the main health and social care qualification requirement for all workers.

Specifically we developed materials and standards about:

- Understanding sensory disability
- Supporting individuals with communication
- Supporting people to move around
- Accessing education, training and employment
- Models of disability
- Multiple disability and conditions
- Using assistive technology
- Assessing individuals
- Promoting awareness of sensory disability



Alison Bennett

However this didn't go far enough and we wanted to be able to offer a specialist qualification to workers who didn't need to do the health and social care general qualifications but did need access to a more specialist pathway so we developed a suite of modules that became a specialist qualification in its own right at under graduate level.

This new qualification is available to any individual wishing to develop their skills and knowledge in our field. It is made up of mandatory and optional units. All of the units in the generic qualification are included plus:

- Supporting people with independent advocacy
- Supporting people with housing choices
- The anatomy, physiology, pathology and demographics of sensory disability
- Using policy, legislation and

- guidance to secure services
- Supporting people with technical and medical interventions
- How children and young people develop
- Understanding Deaf culture
- Supporting individuals with well being and mental health
- Your professional practice

So you will see that this list of units provides the worker with a comprehensive set of options in order to develop the skills and knowledge they are likely to need in order to support someone with a sensory disability.

How is our work being used?

Our work is being used by deafblind people, learners, employers, awarding bodies and sector skills councils to bring about an increase in the skills and knowledge levels of the workforce. So far the units are too new for us to be able to know how many people have undertaken them. But in Wales and Northern Ireland the unit on understanding sensory disability is compulsory to all workers so we can assume that the reach will be quite significant in these countries.

What else is available?

Of course these aren't the only qualifications available to workers supporting deafblind people. Several academic options are available to the workforce including the Certificate and Diploma in Deafblind Studies recognised by the Open University, our programme for intervenors, recognised by the University of Northampton and the Multi Sensory Impairment programme at the University of Birmingham.

With the qualifications we have developed for the health and social care workforce and the

Using the UK system of vocational training to shape workforce development in our field

Subject area	Level 2	Level 3	General Level 5	Specialist Level 5
Understanding sensory disability				
Supporting individuals with communication				
Models of disability				
Multiple disability / conditions				
Using assistive technology				
Supporting people to get around				
Accessing education, training and work				
Assessing individuals				
Promoting awareness of sensory disability				
Independent advocacy				
Housing support				
Anatomy, physiology, pathology and demographics of sensory disability				
Using policy, guidance and legislation to secure services				
Technical and medical interventions				
Positive outcomes for individuals				
Children and young people's development				
Deaf culture				
Well being and mental health				
Professional practice				

academic qualifications available to the general public, we now have a rich package of options for our workforce, but we can always do more. What can we learn from each other across the international community?

Is there value in shared discussion?

I think there are some useful questions we could explore together across the Dbl community

- How do other members of the Dbl community develop vocational skills and knowledge in their workforce?
- What opportunities are there for

collaborative working across the Dbl community to strengthen the range of options on offer to the workforce?

- Can the experiences of Sense provide any helpful pointers for other nations?

This is a subject close to my heart. I would be really keen to hear from anyone who is interested in exploring some of these issues together.

Alison Bennett
Head of Staff Development (alison.bennett@sense.org.uk)
Sense UK (www.sense.org.uk)

Speech-to-Braille interpreting for hearing and visually impaired and deafblind people using JAWS software

The SNAB advice centres for hearing and visually impaired and deafblind people, working together with Accesstech AG in Lucerne, have developed a speech-to-Braille interpreting system for deafblind people using JAWS software

The adaptation of Braille to computer technology has existed some time. But until now, it was only possible to write and read at the same position in the text. Anyone who in the past relied on: a) having detailed information or even whole presentations in spoken language in spite of their being hard of hearing, b) sign-language in spite of their visual impairment, c) spelling out on their hand using the Lorm alphabet can now read the information from a Braille display.

A companion, communication assistant or speech-to-text interpreter is still needed to type the spoken information into a file on a Personal Computer.

The hearing and visually impaired or deafblind person

can read the information at their leisure using the Braille line. Two people can read or write at different speeds and start at different points in the text.

For hearing and visually impaired or deafblind Braille readers, the information is presented in full Braille. Numbers can be reproduced in computer Braille and simple groups of letters can be abbreviated.

Requirements:

- Laptop with Windows XP, Vista, 7 or 8
- Microsoft Word 2003, 2007, 2010 or 2013
- JAWS Version 10 to 14 with a Braille display installed
- Accesstech JAWS add-on Version 1.20 or higher (www.accesstech.ch/atjaws.exe)
- This add-on is integrated into the latest version of JAWS.

Hearing and visually impaired or deafblind people must provide their own hardware and software when



using this new technology at an event.

We are very pleased that this new technology will improve access to live, spoken information for individuals with this disability.

Mäde Martha Müller
(Mueller@szb.ch)
SZB/SNAB (www.szb.ch)



Swiss National Association
of and for the Blind

¹ SNAB – Swiss National Association of and for the Blind - www.snab.ch

² www.accesstech.ch

³ JAWS (Job Access With Speech) Talking software – www.jaws.it

⁴ LORM – Tactile sign language named after Hieronymus Lorm, pseudonym of Austrian deafblind poet and novelist Heinrich Landesmann (1821-1902). www.jewishvirtuallibrary.org

⁵ braille display or braille terminal is an electro-mechanical device for displaying braille characters. www.wikipedia

Mary Guest, founder of Sense's Usher syndrome programme, has passed away



Very sadly, Mary Guest passed away on Thursday 28 March, 2013. Mary is remembered by many for her incredible commitment to people with Usher and their families.

She joined Sense in 1983, launching an Usher Awareness and Education Programme, and she never looked back.

The work that followed was rich and varied - supporting individuals and their families, establishing international networks

on Usher, running arts weekends, setting up support groups, sending out newsletters, sharing new knowledge about the Syndrome, putting together research projects, just to name a few activities. Whatever she did, she did with a passion and she leaves behind a great legacy.

Gill Morbey, Sense's CEO, remembers her contribution:
"Mary was a true professional championing her 'cause'. She passionately

supported people with Usher syndrome, developing and leading research projects and campaigning for services. She was an inspiration not just in the UK but internationally.

I knew Mary over many years but one of my fondest memories was travelling to a conference in Mississippi with her in the 1980's. The population in that area have a high incidence of people with usher syndrome and I spent most of the long haul flight with Mary 'lecturing' me about usher, genetics and how in the future we could at least stop the deterioration of sight. Her passion kept me engaged for hours. We are now looking at stem cell research so I think Mary was well before her time."

"She passionately supported people with Usher syndrome, developing and leading research projects and campaigning for services"

Secretariat News



Meetings

The Dbl Management Committee met in Ahmedabad India in April for its first meeting of 2013. Following the meeting, ManCom attended the 2nd Joint Asian Conference of ICEVI & Dbl. The conference was a wonderful event and the relationship between Dbl and ICEVI was further strengthened through the process of collaboration. We take this opportunity to thank Akhil Paul and Biju Matthew from Sense International India as well as Dr. Bhushan Punani of the Blind People's Association for their invaluable support in the lead up to our meetings and the conference.

Conferences

2nd Joint Asian Conference of ICEVI & Dbl

Congratulations to the International Council for Education of People with Visual Impairment (ICEVI), Blind People's Association (India) (BPA) and Sense International (India) (SII) for hosting an outstanding conference in Ahmedabad, Gujarat in April 2013. The theme of the conference was "Towards an Inclusive Tomorrow". Delegates from all

over the world attended the event which added to the diversity of discussions. Dbl was very proud to be aligned with ICEVI on this conference and looks forward to collaborating on future initiatives.

Dbl European Conference 2013

The 8th Dbl European Conference in Lille is taking shape and we commend the hosts for the wonderful job they are doing in preparing for what is sure to be an innovative and exciting conference. There is still time to register and we encourage you to visit to conference website www.dbilille2013.eu to learn about the program, topics, themes and pre-conference options.

Dbl World Conference 2015

We are delighted that Sense International UK /Sense International (Romania) will jointly host the 16th Dbl World Conference on Deafblindness. The 2015 conference will take place in Bucharest, Romania. While the timing has yet to be finalized, the tentative dates are May 25-30, 2015. Hosting the conference in Central Europe will raise awareness of the successes and challenges for deafblind people in Romania and more broadly in the region.

We congratulate them for their successful bid and wish them every success with the conference.

Dbl European Conference 2017

We have called for Expressions of Interest to host the 9th Dbl European Conference in 2017. We received two excellent applications and we have called for full bid applications from the interested parties after which they will be presented to the Dbl Board for ratification. The successful applicant will be announced during the conference in Lille.

Membership

Dbl recognises that the success it achieves worldwide greatly depends upon the support of its individual and corporate members to promote awareness and services. Thank you to the many members who have renewed their membership to Dbl this year. We are delighted to welcome new members this year from Iceland, Ireland, Germany, Denmark, UK, USA, Ethiopia, Zambia and Canada.

If you know of an organization who should be a member of Dbl we would be happy to send them a letter of invitation. Please pass on any suggestions to secretariat@deafblindinternational.org.

Keeping in touch

We want to hear from you! Information sharing is essential to Dbl and is what keeps the organization strong and current. If you have information you want to share with others or if you're looking for a contact in a faraway place, please send us an email and we can work together to find a solution.

Elvira Edwards & Bronte Pyett
Dbl Secretariat.

The Countdown begins for the 16th Dbl World Conference on Deafblindness

Staff from Sense International (Romania) together with staff from Sense International (UK) are in the early stages of preparing for the next Dbl World Conference to be held in Romania in 2015. Although not completely finalized, the tentative dates are May 25-30, 2015.

Bucharest, the capital city of Romania and also its largest metropolis of two million people, has been selected as the host city

for this event. Once known as "The little Paris", this city has been booming of late, with changes creating an interesting blend of old and new.

We anticipate a wonderful conference hosted by Cristiana Solomie and the rest of her energetic staff at Sense International in Bucharest. If all the wonderful developments on behalf of deafblind children they have been able to achieve in recent years

are any indication, we should be prepared for a great conference. Watch for further information on the Dbl website (www.deafblindinternational.org) and Dbl Facebook page (www.facebook.com/dbiint) regarding the conference theme, call for papers, confirmed dates, venue, range of accommodations and registration fees for the 16th Dbl World Conference on Deafblindness.

Dbl Board Membership 2011-2015

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The Management Committee for the 2011-2015 period includes the two elected offices (President and the two Vice Presidents), the Past President, the Information Officer and the Secretary:



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MEMBERSHIP OF DBI IS OPEN TO:

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Individuals
Libraries and Universities



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