

## **Dbl Review**

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Deafblind International was formerly known as the International Association for the Education of Deaf-Blind People. Dbl Review appears 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 and drawings are welcome; they will be copied and returned. All written material should be in the English language and may be edited before publication. It should be sent for publication to arrive by the date below. Opinions expressed in articles are those of the author and should not be understood as representing the view of Dbl. Dbl Review is also available in text-only format in the form of an electronic file. If you are interested in receiving your copy in this format, please contact: the Dbl Secretariat.

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Cover: An Outdoor Network Adventure in Scotland

## **A message from the president**

Dear Friends and Colleagues,

As ever this is a news packed issue of the Review illustrating, once again, the amazing work that you all do. I can only give you a brief outline of some of the things I have been involved in. Huge thanks to Ton Groot Zwaafink for all his work and support as Dbl Treasurer. We will miss Ton but Kentalis continues their brilliant support through Frank Kat our new Treasurer. Ton assures the Management Committee that he will not be a stranger so I have a feeling we will be seeing him at future Dbl conferences and events. Nevertheless, I offer a big welcome to Frank. We were delighted to have our two day management committee meeting prior to the ADBN conference in Lund, Sweden in early November. Congratulations to Henrik Brink, Chair of the local planning committee and Liz Duncan Chair of ADBN and the scientific committee for making the conference such a success. Organisers, participants and presenters all contributed to a remarkable event which Dbl was delighted to be associated with.

With my other 'hat' on and speaking from the Sense UK perspective we are delighted to host the 10th ADBN conference in Belfast, Northern Ireland in 2014. There will be more on that in the days ahead leading up to this important event. Dbl has also been working on our strategic plan and to take this forward a number of us met in London in October. One of the key activities was the beginnings of a fundraising plan. It's a sad fact that while all our dreams are important, and we certainly can do a great deal without money, we still need a bit more finance to help us on our way. There is much to do here but I'm pleased that we have made a great start.

Our next management committee meeting will be associated with the upcoming Asian conference being held in Ahmedabad India in early April. Of course it will be great to see the full Board at the European Dbl conference in Lille, late August 2013. I have been on a range of other travels for my Sense job but of course I spread the word of Dbl as I go!

Kindest regards to all

Gillian Morbey

## EDITORIAL

Dear friends,

Welcome to the 50th edition of Dbl Review; a milestone publication of Deafblind International. The first edition was published twenty-five years ago in January 1988 under the name Deaf-Blind Education, the Journal of the International Association for the Education of the Deaf-Blind – the organization's former name. The publication's name was changed with the printing of the 21st edition of Dbl Review (The Magazine of Deafblind International) in January, 1998.

A sample of articles published in the 24 page first edition included the following: Assessment of Vision in Deaf-Blind Individuals (Lea Hyvarinen-Finland), An Experiment in Sex Education (Mrs. Beroz Vasha-India), Integration (John McInnes-Canada), Report on the International Conference at Poitiers, Project Nordic Directory for Staff to Deaf-Blind Services, etc. The publication included a report from the Chair (John McInnes) and reports from Nigeria, Greece, Australia, France, Malta, Canada, UK, Singapore, Bahamas, the USSR, etc. The editor of Deaf-Blind Education in 1988 was Paul Ennals from Sense.

The content of this edition generally follows that of the first editions presenting a balance of science related articles, reviews of recent conferences, announcements of upcoming conferences and reports of developments in various countries.

I repeat what I have said in this column, how exciting it is as editor to present such an array of material collected from around the world. In this edition, articles and announcements were received from Argentina, Australia, Canada, Denmark, Finland, France, Germany, Guatemala, India, Ireland, Japan, Jordan, Kenya, Malawi, Netherlands, Scotland, Sweden, Norway, Uganda, UK and USA.

I wish to commend the organizers of the recent ADBN Conference (Independent Dependency – Living in Two Realities) held in early November in Lund Sweden. Check out the two articles from that Conference that are included in this edition. I was particularly intrigued by Anne-Maj Magnström's dependency on modern day technology to help with her independence. Gunilla Ronnblom's paper on 'Life Adjustment – an inner process over time', a summary of a book by the same name, is an excellent description of the various adjustments that people with acquired deafblindness live through.

A good read is Barbara Mason and Martha Majors paper 'After Laura and Helen', which depicts some aspects of the changing face of the school age population of children with deafblindness in the USA. The results of their study would be similar to what is observed in the classrooms of other countries where rubella is but an incidental occurrence.

I wish to acknowledge the efforts in Argentina to develop an independent living residential service for a group of congenital deafblind young adults. This achievement is a breakthrough in this part of the world where disabled young adults leaving the family home to live independently is more the exception than the rule. Hat's off to parent and professional Aurea Soza for her courage to pursue this venture in Argentina.

There are numerous interesting County reports in this edition. The report from Jordan, in the Middle East was particularly inspiring as the Middle East is an area with little voice in the deafblind world. In this article, we read that under the auspices of the Arab Episcopal Church in Jerusalem and the Middle East, the Holy Land Institute for the Deaf is helping Hard of Hearing, Deaf and Deafblind people participate meaningfully in family and community life. The author reports that this inclusive school is the only one of its kind in the Arab Middle East.

I suggest you take a close look at the excellent Network reports. The first report from the Outdoor Network makes one envious of the adventure that the group of deafblind adults experienced in the Highlands of Scotland last September. Thanks to Joe Gibson from Sense Scotland for heading up this event. Congratulations to Riita and Russ for their Social-Haptic Communication Network joining the DbI Network family.

I thought it fitting to include the article celebrating the life of Peggy Freeman, co-founder of Sense. Peggy of course was one of the giants (definitely not in stature) in the deafblind field, advocating, as a parent, for deafblind programs for children with congenital deafblindness.

Congratulations to the Sense International group in Romania for winning the privilege of hosting the 16th World Conference in 2015.

Stan Munroe

### **Bernadette Kappen reports:**

Learning is always a part of what we do as professionals working with individuals who are deafblind. Deafblind International helps us stay connected, and through the local, regional and world conferences we can share our skills with colleagues as well as learn about new approaches. In the next few months there are two opportunities for us to network with colleagues and friends. The joint ICEVI and DbI regional conference in Ahmedabad India from April 5 – 7, 2013 offers an opportunity to see what is happening in the Asia region. Many programs have developed in this area of the world over the past 10 years and the information will be of interest to everyone. The European Deafblind Conference is scheduled for August 24th to 28th, 2012 in Lille, France. The European Conference brings together people from around Europe as well as around the world. This is an opportunity to share activities and learn from many of the leading experts in the field. Both these conferences provide high level presentations and besides the knowledge that is gained the conferences bring together people interested in individuals who are deafblind. The networking is

invaluable and gives us increased energy and enthusiasm to return to our daily work.

It is no secret that we live in a complex world of constant change, increasing demands, and more competition than ever before. Things are spinning very fast and we need something solid to hold on to. The values and beliefs of your organization help with this and your participation at Dbl events should also provide some guidance. You have a vital role to play in your organization and as a member of Dbl. You support Dbl by sharing your experience and beliefs at events. We thank you for all you do.

At the conferences we honor individuals who have made contributions to Dbl and to the promoting the needs of individuals who are deafblind. Over the next few months, you will see information on the website where you can nominate individuals to receive awards given by Dbl. Please check the website and nominate individuals for the awards.

### **Carolyn Monaco reports:**

Wow, what an energizing experience it has been to read this, the 50th issue of the Dbl Review as it has come to fruition and final publication. Working with Stan on the final product ensures that I schedule in the time to read every page and I can't begin to tell you how pleased I am to be able to do that. Your interesting, informative and heartfelt articles and pictures continue to be a constant source of motivation and intrigue. 2013 promises to be an active and exciting year for all of us at Dbl. Best wishes to everyone!

### **“A good senior life with a combined sight and hearing loss”**

**On 6th November 2012 the Nordic Centre for Welfare and Social Issues hosted an international conference in Lund Sweden on the topic “A good senior life with a dual sensory loss”, as a preconference to the 9th Dbl ADBN conference. The following is a summary of remarks from the three speakers.**

Opening Remarks – Barbro Westerholm, Swedish Member of Parliament  
Swedish Member of Parliament Barbro Westerholm opened the conference and participated throughout the day. In her opening remarks, Barbro indicated that we currently have the oldest population that Sweden has ever had. Whereas the age

demographic in earlier days was similar to a pyramid with many youngsters at the bottom and gradually fewer older at the top; it is now shaped like a skyscraper with the old people on top, looking down upon younger generations. This means also that people with a dual sensory loss are a growing group with individual needs that are too easily forgotten.

Barbro Westerholm continued by stating that communication is the key; however life is no life without communication. While common sense tells us what we should do, sometimes budgets and finance ministers say otherwise. In the long run, however, it may be even more costly to society if we ignore these challenges now and save them for later.

On dementia and deafblindness – Arlene J. Astell (School of Psychiatry, University of St. Andrews)

Arlene Askell, an expert in this field, spoke about dementia and the scope of its influence. For the person with dementia, it affects his or her personhood. For the person's family this condition affects their relationships with the person affected. When relating to staff assisting the person, dementia has imposed a very negative influence on the development of relationships.

In many nursing homes it has come to the point where communication with people with dementia is something which takes place only during set times.

“Communication should be a normal part of life, not an activity” Arlene stated.

She also suggested that it is not entirely necessary to know about the past life of the person with dementia when working and conversing with them; instead using photos and music from their youth can often be used to initiate and carry on conversations.

Arlene J. Astell (together with Maggie P. Ellis) has written an article titled ‘Communicating Beyond Speech’ explaining a system of intensive adaptive interaction to enable improving communication between people with dementia and those that care for them. The article is published in the most recent inspiration booklet A Good Senior Life with Dual Sensory Loss available from the Nordic Centre for Welfare and Social Issues.

For an English copy of the publication, contact the centre at [www.nordicwelfare.org](http://www.nordicwelfare.org) or download at:

<http://www.nordicwelfare.org/Publications/Inspirationshefter/A-Good-Senior-Life-with-Dual-Sensory-Loss/>

A good life with dual sensory loss

Megan Mann (Sense UK) invited the participants to reflect on what we would wish for when we reach the autumn of our life?

We were introduced to three persons, each with vision and hearing loss. We learned about their individual wishes and reflections about their very different personal situations. For example, one lady living in a residential home felt she had very little contact with staff and other residents and repeated a wish to die!

Megan indicated moving to residential care is a transition that many people find difficult. While there are physical and psychological adjustments to be made for

everyone, it is far more difficult and challenging when the individual has a significant sight and hearing loss.

Megan quoted various family members and deafblind persons saying that they would not be so lonely if they were in the company of others living in a residential home instead of living by themselves. Unfortunately, the reality of this situation is often not the case. Residents often report greater difficulty orientating oneself in a much larger and complex environment, complicated by strange sounds, different voices and accents and changing staff members.

Megan asked the group:

- Can we always change the way things are for people in this situation?

Possibly.

- Can we do anything to improve their quality of life? Yes, sometimes.
- Can we motivate individuals to enjoy life again? No, not always.
- Should we accept and adopt the view – “I want life to end”?
- Can we listen without judgement and accept those feelings whilst being alongside the individual? She suggested that it is essential to do that and to acknowledge how desperate some people can feel.

Megan suggests that one role of the professional is to be the reflective detective. Often there are very sensible explanations to how someone is reacting.

As professionals we can sometimes experience ‘client myopia’. We focus on the person we see immediately in front of us, in the here and now, without paying much attention to the history of the person; what has made them the person they are today.

Megan concluded her presentation by reminding us that time is one-directional. We start to age the minute we are born. So we are all heading in that direction, and for most of us our sight and hearing will be affected to some extent.

Frank A. Clark, an American minister and writer, once said: “We’ve put more effort into helping folks reach old age than into helping them enjoy it.”

Megan ended her presentation by asking professionals who support older people, that when the sight and hearing of the persons fail, that we do not fail them too.

Liz Duncan (Sense UK) emphasized that professionals working in the deafblind field and professionals working in the area of dementia share the same values and challenges.

Politicians are concerned about the cost of the growing population of persons with deafblindness as well as the increasing population of persons with dementia. She suggested that some common factors that deafblind people with dementia share with one another include a lack of communication with staff and other residents and general deprivation and isolation. One cannot dismiss that there is a certain reservation or unwillingness by staff to communicate in alternative ways with these individuals. Liz suggested that some staff members have a natural talent for alternative communication; some are willing to learn it, but admittedly others have difficulty doing so.

Liz suggested that deafblind practitioners should use their professional skills as best they can to support ageing persons with deafblindness to continue to be independent and share their life experiences and passion for life.

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**Interview with Ken Barrett (UK, age 88), during the preconference “A Good senior Life with a Combined Sight and Hearing Loss” in Lund Sweden, November 6, 2012**

Ann: I was very impressed about your life story and what Megan told about you at the preconference, about your hopes, dreams and aspirations. What makes you enjoy life?

Ken: My aim in life is to be as independent as possible, but also to help other people that are in the same position as me, deafblind, to show them that there is something else to life than being deafblind.

Ann: Do you have an opportunity to do that?

Ken: Yes, I do. I am chairman of a blind society club with over 40 members, aged between 70 and 90, and we discuss things I learned from classes. And I share those little things that I have learned such as: How to be safe in the kitchen, how to use a knife safely, and how to use a microwave.

Ann: Are you living alone and cooking by yourself?

Ken: Yes, I cook by myself, and I make wonderful cakes. I take them to the forum and let them taste them and I tell them that I have made them in a microwave.

Ann: How did you learn this?

Ken: I am an ex-service man and a veteran from World War Two. There is a charity organisation now called Blind Veterans UK. That charity looks after blind ex-service men and women. They have centres in Brighton, North Wales and Sheffield. You can go there for a week and get an introduction course. They introduce you to independent living, like kitchen tasks, mobility, using the computer. They can supply you, if you wish, with a computer, printer and everything. The organisation works with contributions. It was founded during World War One. They also have holiday centres with medical care. Nowadays you don't need to be blinded by war to use those centres; people with other eye diseases can go there.

Ann: How do you get your information about the world? Are you able to listen to the radio or television?

Ken: For listening to television, I am using a loop-system in the house. For radio, you can use a radio called Sonato especially for the blind; it is linked to your computer.

Ann: Do you listen a lot to the radio?



Ken: Yes, I do. I have sleeping problems, so I listen a lot to the radio. Another thing we have is the fire brigade; they put special smoke alarms in our house, with vibration, and you put them under your pillow.

Ann: And how about reading?

Ken: I belong to the Royal National Institute for the Blind; they have a talking book service.

I have a Daisy player, and they send me six books per week. You can tell them which interests you have, but I don't read all of the books I get. I use a scanner with my computer with which I can read my correspondence, using voice recognition as my input. That works fantastic. I also write articles. When I go back home, they will ask me to write an article about this conference.

Ann: Do you also have assistance if you go outside or around the house?

Ken: I have a guide-communicator that I have to pay myself. I have six hours of assistance per week that I can spend as I want. They go shopping with me or to the bank.

Ann: Are there things you would like to do that you cannot do?

Ken: Each person has unfulfilled wishes like seeing the countryside again, seeing trees, hearing the birds. When you have my age of almost 90 years old; you don't have many unfulfilled wishes. You hope that you can carry on. As you do know, helping other people also gives you deep satisfaction. For instance, I met someone about 45 years old, with a teenage daughter. She was horseback riding and had an accident and lost her sight. That had a big impact on her and she did not want to do anything anymore; was afraid to go outside. So I talked to her husband, and asked him to bring her to me; so now I can help her by using the computer and finding the right software so she can do more.

I am also getting a new family member- a guide dog. I have been waiting for two years. I tried four dogs and after that they asked me if I had a preference for one dog, and I did. So I hope she will come soon. I never had a guide dog before; I used to walk with a long cane and I am using the Tracker Breeze (GPS). I know five or six different routes, but sometimes assistance is handy by busy roads. It will be a great difference to me, for it also means a companionship. During long winter nights, when there is nothing on the radio, a dog gives the possibility to get out.

I am quite happy living on my own. But I like to take any opportunity I have to socialize, to meet people. But nowadays there are a lot of people that ask me to come and talk, which is taking up a lot of my time now. And I am also made a trustee director of a big charity that has board meetings five times per year; so there are a lot of things that keep me off the street. I have also written a book so if you like to read it.

Ann: I would love to. Do you read Braille?

Ken: No, I don't read Braille. I have asked at the charity organisation, but they said that Braille was a dying language and that they don't learn it any more. That's really a pity for I would have loved to learn it.

Ann: Thank you Ken for taking the time.

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## **ADBN Lund**

### **ADBN Lund, 2012 was one great 'Reality'**

Congratulations to the ADBN Coordinating Committee and the Local Planning Committee for the successful 9th Dbl Acquired Deafblindness Network Conference held in Lund, Sweden November 7-10, 2012. This marked the first time this event has occurred in Sweden, previously having made its way around most of the northern European countries since the first event took place in the Netherlands in 1994.

As a portent of what was to come, the conference got off to spectacular start with a tight rope balancing act, demonstrating the Independent Dependency theme of the Conference.

The committee worked their magic with their six plenary sessions together satisfying the conference theme: Independent Dependency – Living in Two Realities. Without exception, the plenary sessions, which ranged from: theoretical discussions, practical applications through technology, the transfer of medical expertise, inter and intra personal relationships and personal life adjustment to the disability, carefully explored the delicate balance between the deafblind person sustaining their personal independency while experiencing a growing dependency on other people and technology to carry on their daily life.

To complement the plenaries, a complex array of 36 workshops were held on topics that varied from "theory of mind", a vibrotactile aid to improve environmental perception, empowerment for deafblind seniors, tips for trainers, anxiety and depression; and the list goes on. For the complete conference proceedings, including the program, workshops and plenary manuscripts, go to the conference website: [www.skane.se/adbn2012](http://www.skane.se/adbn2012)

The conference was well attended, with 189 persons registering from 14 countries. The conference participants came from the following countries, in order of the number registered: Sweden (82), Netherlands (26), UK (24), Norway (23) and Denmark (12). The remainder represented Switzerland (5), Australia (4), USA (4), India (2), Ethiopia (2) and 1 each from Russia, France, Canada, Peru and Cote d'ivoire.

The conference venue, the Scandic Star Hotel with all its amenities, was a superb location. The food, including the breakfast and lunch buffets, as well as the “gourmet” dinners, added a further lustre to this event; thanks to culinary guru, Jamie Oliver.

And who can forget the closing session, featuring a surprising visit from several ABBA “stars”, Superman (woman) and a great band which kept the place rocking to the wee Swedish hours.

The coordinating committee announced that Belfast Ireland would be the location of the 10th ADBN conference sometime in the last quarter of 2014. More information will be coming out in the months ahead.

Stan Munroe

DbI Information Officer

## **Independence and autonomy with new technology**

**Plenary Presentation, ADBN Conference Lund, Sweden, Nov. 09, 2012**

Anne-Maj Magnström, Association of the Swedish Deafblind

### Introduction

I'd like to thank the ADBN planning committee for inviting me to speak at this conference. Giving a speech in Swedish sign language is a big challenge for me – I can't hold the script and read it; my eyesight isn't good enough. And I can't read Braille fast enough. So I've worked to memorize the speech, and I've got my deafblind interpreters and the microphone by my side.

Assistive technology is designed to make daily life easier for people with disabilities. In Sweden, you don't buy assistive devices in shops; you obtain them through prescription or from the county council. Consumer products, on the other hand, are available to anyone in shops, but they are usually not adapted to our needs. But times have changed, and that is the focus of my presentation.

Following a resolution at its 2011 conference, the Association of the Swedish Deafblind (FSDB) formed an Internet Technology Issues taskforce. The idea behind its formation is that persons with deafblindness have been left behind in what has become a very rapid development of new IT products, particularly smartphones and tablets. Based on touchscreen technology instead of physical keys and buttons, these devices can prove inaccessible to unaccustomed users.

Formed in November 2011, FSDB's taskforce on IT issues comprises four women and three men. The group members are of different ages and have various vision and hearing impairments using different methods of reading and communication. The group includes deaf sign-language users, with or without residual vision, and hearing-impaired people, with or without residual vision.

Since Apple's iPhone and iPad already offer built-in screen readers and synthetic speech as standard, plus connectivity for Braille displays, this was where the group

started. It soon became apparent that the iPhone was a better choice for blind people using synthetic speech and Braille. However, deaf people with vision impairment were better helped by the iPad's larger screen for picture messaging others with the same or similar equipment.

Both products feature many apps to facilitate reading books and newspapers, GPS navigation, scanning and processing text with OCR software. Amongst many other benefits, this makes them accessible to vision-impaired people. They can be downloaded free or at very low cost from Apple's App Store; they are simple to download and generally very easy to use.

That said, this equipment is based on a technology developed entirely for sighted and hearing people. Despite built-in screen readers and other refinements, new skills are still needed in order to use this new technology. Training is required to make it accessible to persons with deafblindness.

### How this new technology has changed my life

What I'd like to talk about now is how the new technology has changed my life personally, for both work and play. I've always loved reading and learning about things, ever since I was a child. Technology was, and still is, very exciting to me, until I started having difficulty reading. Suddenly I was no longer the family's IT expert. Our daughters grew up and took over that role. When my husband, Jan, bought his iPhone, I watched him playing with it and thought, "That's the end of technology for me." But I was totally wrong!

I got my own iPhone in November 2011. My husband had to help me with the installation, which felt a bit depressing. But then I continued on my own. I used a video magnifier to operate my iPhone until I got help to connect my Braille display to it. Right away, I realised it was much easier to work with compared to using screen reader programs on the computer.

Apple has integrated several types of assistive technology into its mobile devices, including VoiceOver, which includes speech synthesis, and Braille displays. VoiceOver is also a feature on Apple computers. Zoom, large text and inverted colours are also helpful and are quite easy to activate using gestures and the button on the iPhone and iPad.

As I have already mentioned, smartphones and tablets have touch screens instead of physical keys and buttons, which makes them difficult to use for those of us with visual impairments. We need to know about what special accessories are available, such as various keyboards – wireless or docking.

A large number of Braille displays are available for iPhones and iPads. My fellow testers and I advise you to choose a Braille display with a Braille keyboard, which minimises the amount of equipment you need to carry with you.

The iPhone has a useful built-in vibrator, but the iPad doesn't. I got to test a transmitter that you can plug into the audio output of the iPad, which notifies my wristwatch of incoming phone calls and emails.

Around New Year 2012 – just weeks after getting my iPhone – I received an iPad. I had agreed to test consumer products and services on behalf of my county council, which is taking part in a two-year government-commissioned project at the Swedish Institute of Assistive Technology to look into how people with disabilities can benefit from consumer products instead of prescribed assistive technology for communication.

A technician from the county council had been sent to my home to fix a computer problem, and brought along an iPad for me to test. I opened the packaging and started to install it myself, which I'd learned how to do from using the iPhone. I activated assistive technology in the iPad immediately, and the only thing I needed help with was keying in the code for the Braille display.

Meanwhile, my husband and I bought iPhones for all three of our daughters, which would make it easier to keep in contact. This was very timely, because my eldest daughter was just moving from our home town in northern Sweden to Örebro, 200 km to the south, for upper-secondary school studies. Thanks to her iPhone and my iPad, we kept in contact a great deal, even having virtual coffee breaks together.

What kind of training and support did I have?

I was able to discuss issues with my fellow testers in FSDB's IT group. I 'googled' information when necessary. Later I discovered that PDF files were easier to read using the iPad than the computer. Since then, I've continued to use the iPad for this, both at work and at home. I now know a lot about it, so I help others who are deafblind, as well as friends and others.

It's wonderful being able to stay connected, take part in social media, share pictures, and to search for and select information yourself. The devices can tell you your geographical position when you're travelling and I no longer need to take my work computer on my travels, so my rucksack is much lighter. I keep in touch with my family, too. I've also noticed that I use my computer at home much less.

How can a small gadget with a touch screen change so much for me? What's in it and what apps have I downloaded to my devices? Apps are programs for smartphones and tablets. The devices come with standard apps such as a telephone, text messaging, email, a clock, weather reports, a compass, a photo album and a camera. The built-in apps differ slightly between the iPhone and the iPad. In both devices you click on "App Store" to download free apps or buy other apps. Let me tell you, apps are like candy! It's so much fun to find new, useful apps that work with VoiceOver and assistive technology.

As I mentioned, smartphones and tablets have changed my work and play. My vision had become so poor that all I could read was white text on a black background in a large font size. I often thought that my video magnifier – huge and stationary – was the final option left to me if I wanted to experience the world. I spent hours sitting at the computer and the video magnifier. Then my eyes started getting tired from that reading and I practised reading in Braille, trying to increase my speed and the amount of material I read that way.

I couldn't see the "best before dates" on anything in the fridge. I couldn't see travel information at railway stations. I couldn't communicate with people using pen and paper when that was required.

Deafblindness makes communication, information and orientation difficult. These are the three categories for which I'd like to show you apps.

In the autumn of 2009 I started having problems using my old mobile phone. I had trouble getting started using the Braille display with it. But today I much prefer to send text messages using my iPhone, which is easy to handle with a Braille display. I can also choose to reply using my iPad instead.

I was previously used to making video calls with a small mobile phone, but then I lost interest in it. But not anymore! I can use the iPad for video calls via FaceTime, Tango and Skype with my family and some of my friends. I can chat via Skype, Messages and Facebook Messenger if necessary.

I use social media frequently, keeping in touch with family, friends and colleagues on Facebook. I share my pictures on Instagram; preferably with my iPad because its display is larger. And I can still communicate manually with people when I have to, using the Handwriting function.

This year, 2012, is the first year I haven't used a physical planning calendar. I'm currently learning how to use the Calendar app on the iPhone and iPad, which is synchronised with my computers at work and at home.

I love taking photographs! I take them using the Camera app. All devices have a Pictures and a Notes app. And I've discovered the advantage of photographing things and enlarging them – it's like using CCTV or a video magnifier. When I take a photo using my iPhone, I use the iPad, with its larger display, to browse the photos. The Notes app is excellent to use if I need to write and save something. The notes I write are saved in my computers and iPad or iPhone simultaneously.

At last I can read the news like everyone else, although not to the same extent. With Free RSS Reader I select the newspapers whose newsfeeds I want to subscribe to, and I can choose whether to read them in my iPhone or iPad.

Any documents I need over a period of time can be saved in Dropbox, a type of cloud service. I can access my Dropboxed documents on all of my computers and devices.

I always open the Weather app to check the weather and temperature before I go out with my guide dog.

I usually travel by train, which can sometimes be an adventure if you're travelling alone. A Swedish app called Tågavlan (Train Schedule) tells me which platform I need to go to, and so on.

The view from train or taxi windows has become increasingly misty and blurred to me. I sometimes recognise places, but usually not. To be sure of where I am, I use Position. If I encounter a problem, I simply, click SMS to send for help.

For Mother Nature's sake I like to save paper where I can, and have found a good way of reading paperwork for meetings using the Pointer app. Sometimes when I see something beautiful or unusual, or if something funny happens, I take a photo using my iPhone or iPad and use an app by the Swedish Postal Service to turn it into a physical postcard. I open the app and write a few lines and the address. I then pay for and send the postcard. An eternal bookworm, I now borrow books from my local library using BlueFire Reader and read e-books on "white on black" on my iPad. I also read books in iBook using the Braille display.

## Conclusion

Let me name the most important factors that will allow technology to improve quality of life for those of us who have deafblindness.

- Firstly, we need a good introduction to the product and the opportunities it offers. This introduction should thoroughly describe and adapt the product together with the user, who should feel involved in this process.
- Allocate a lot of time to training and support at the start, and the user will greatly enjoy and benefit from using the product. A solid foundation is what makes a house stand strong.
- Communication between instructors and users must be clear and easy.
- Sharing knowledge and experiences with others is equally important. A focus group via email or meetings is a good way of doing this.
- Support is crucial. Assistive technology makes everyday life easier for people with disabilities, but it also causes stress when the person needs support. That's why support must be provided quickly when technological problems occur.
- Don't forget that we all have our own learning curve. Some of us may need to go through several stages, such as needing to adopt a different reading method, needing to use audio description services, and learning how to use the technology.

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## **The Stages in the Life Adjustment for People with Acquired Deafblindness**

presented by Gunilla Henningsen Rönnblom as part of the

## **Plenary Presentation: Life Adjustment – An Internal Process over Time**

**ADBN Conference, Lund, Sweden, Nov 09, 2012**

Life adjustment is an internal process to handle and integrate new conditions, when long-term illness or disability sneaks into life, in this case combined vision and hearing disability. It is a personal and social process of change, running in parallel with the deterioration of vision and hearing, and interwoven with life in general. Life adjustment is more than a crisis. It is about repairing one's self-image and re-establishing the feeling of entirety in life – living your life-story again. You develop a personal know-how, coping with the new conditions, and you develop a skill on changing that strengthens.

Every person has a unique life situation, personal conditions affecting reactions and coping. Despite this, there are similarities in experiences, triggering events and strategies. This makes it possible to describe the adjustment process as a course with stages – each of them lasting for years.

### **Stage I: Holding on**

The initial stage is characterized by the new disability sneaking into the person's life. Looking back, the informants describe a straining and lonely time, where they have been struggling to cope with everyday life. The strategies are focused on hiding and denying the difficulties with vision and/or hearing, which takes a lot of energy. The fact that difficulties are contextual, and that the sustaining power is strong, keeps you from seeking help; suggestions from professionals, family and friends are rejected.

Upon being diagnosed, an overwhelming loneliness shows in the stories. Information and follow up has been purely coincidental, and meeting with the term "deafblindness" is confusing. You are confronted with something that does not make sense, and most of the informants are keeping thoughts and emotions to themselves. Meeting with the term "deafblindness" is impossible to identify with, and can be a barrier to rehabilitation and specific services.

All the informants had a hearing or visual impairment since childhood. It has become quite natural to them. Getting symptoms, or a diagnosis, telling that a second sense is affected, arises fear and anxiety. The informants tell about ways of self-testing vision and hearing. Progression is unpredictable, but you nourish a hope that the functioning level will keep stable.

Troubles with keeping up in conversations, and physical surprises, put the self-image and the ontological security on trial. An increasing stress, resulting from not trusting your senses, but still fighting to maintain a façade, eventually becomes too much. The recognition of what is going on can no longer be avoided.

"I am somewhere I do not want to be and I cannot go back to where I was."

Recognition is not equal with recognizing oneself to be a person with deafblindness. Recognition is about facing two facts: life can no longer continue as usual and the future will not turn out as planned. The connection between the past, the present and the future is lost. Reactions to this insight can be strong and lead to a crisis.



This is a turning point in the life adjustment process. The focus turns from “holding on” to “changing”.

Plateaus and downfalls: The initial stage deterioration of vision or hearing can occur over a longer time period, without the person being overly aware of it. It is natural to adapt life to new conditions without performing certain changes. Gradually, when every-day life becomes more affected, major changes are required to make do. These alternations between periods of acceptable functioning and periods of new challenges arising, we call plateaus and downfalls in this model. Plateaus may contain a degree of deterioration, but at a certain point you experience strategies no longer to be effective. This can also be caused by external changes, natural events in life like becoming a parent, moving or starting in a new job. The informants describe this as losing one’s foothold, feeling anxiety about how to cope with the new situation. These critical periods, we name downfalls. The person is forced into a period of processing, to develop strategies that are adequate to the new situation. A new level of functioning, a new plateau, will then be established. The informants describe these recurring alternations between plateaus and downfalls, to be a significant burden.

## Stage II: Processing and exploring

This is a stage with processing, exploring and learning. You are facing strenuous, lonely and energy consuming work, both physically and mentally. You explore and re-learn to know yourself and your sensory functions, through interaction with the world around you. Fundamentally, this is about making the combined vision and hearing disability become a part of yourself and your life.

This is a period of hope and also doubts. Doubting how to manage all what is new, but also mobilizing power to get on.

Recognizing that life takes another direction than expected, you grieve about the loss and feel anxious about the future. Most describe themselves being all alone processing these emotions. Even if you are acknowledging the new challenges to yourself, this does not necessarily mean that you are ready to talk with others about it. The stories show that you avoid sharing your inner feelings, even with close family – while carrying a strong desire to be understood. You do not want to burden them. Exploring one-self, in different situations and contexts, brings increased awareness about the functional consequences of the disability. A frightening insight is that reduced access to information, formal and contextual, makes it difficult to take equal part in conversations. Challenges in moving around freely, and in keeping up in conversation, pushes the person further in the adjustment process. Carefully you approach other persons with deafblindness, curious about their experiences. It is a big step to take, described as a turning point.

The processing of self-image is fundamental in this stage. It is about adjusting the way you look at yourself, and how others perceive you.

Experiencing that communication and participation varies, depending on the situation, causing uncertainty. For instance: how do others now perceive me? Showing up with visible adaptations, such as the cane or an interpreter, raises the question: “Can people still see what they have always seen in me?”

The self-image as an independent individual might become compromised, as one takes services like interpretation or personal assistance into use. Many informants describe feeling uncomfortable accepting personal support; fearing losing their independency.

Moving on in the adjustment process requires emotional preparedness and energy – especially for meeting with qualified professionals. In the comprehensive work of change, the informants experience a lack of interdisciplinary cooperation and coordination. Naturally enough, it is frustrating when rehabilitation is not based on your expressed needs, or does not take specific needs into consideration, for example when it comes to communication. Energy is limited, which makes it important that the outcome of learning is balanced with the energy spent.

Learning new methods for communication and mobility, taking assistive technology and services into use increases activity and participation. As a result from experiences gained, uncertainty can now be restricted to certain situations or activities; it is now possible to face the future. The personal knowledge you develop helps to restore the inner trust in the person you are – a person with vision and hearing disability/deafblindness.

### Stage III: Rooted in oneself

Now is the time to show the world who you are today. With a more relaxed attitude with assistive technology and personal support, you integrate the experience gained in everyday-life, and make coping strategies become routines. Living your life, incorporating your conditions of deafblindness, you are ready to speak openly about the challenges that it brings, and define your needs to the professionals and authorities.

This may lead to conflicts when you experience being met with ignorance or rigidity by rules, feeling powerless when regulations do not satisfy or fit the expressed needs. Support from peers and professionals who know deafblindness, is of great value to stand one's ground.

With personal know-how and repaired self-image it is now easier to introduce yourself as the individual you are, and to address attitudes when you experience being categorized. The informants relate that making others see beyond the disability is a recurring task.

A result of the life adjustment can mean increased level of activity for the person, which leads to an increased need for services. This can seem to be a paradox to authorities. Some informants tell that you have to fight to get the services needed – in order to live life to your full potential.

This stage is described as finding 'inner trust in oneself', making it possible to live with the uncertainty of what the future may bring. The past, the present and the future are connected again. It is possible now to accept oneself, as a person with a combined vision and hearing disability – or a person with deafblindness. Feeling connected to people with deafblindness is a new social belonging.

Living with Deafblindness through regular maintenance

The last stage is a transition into living with deafblindness through ongoing maintenance work, experiencing reoccurring adjustments. You have faith in your ability to cope – but uncertainty is a part of life. No matter how successfully persons go through the adjustment process, external conditions such as access to services and assistive technology, to a large degree determines the level of activity and participation.

Most informants mean that the experience of vulnerability and helplessness is something one can't quite control.

Continuous adjustments are part of life. Events, such as having new work schedules or children changing school, require adjustments. Changes in regulations and services can ruin established routines. In addition, there are downfalls due to deterioration of sensory function.

The ongoing maintenance work includes continued contact with professionals, and keeping up to date with the latest developments in assistive technology and medical research. Some claim this is mostly up to them-selves. Those who are in contact with specialists on deafblindness, specify that this eases their situation.

Combined vision and hearing disability/deafblindness implies double work "back-stage", which is invisible to others and therefore difficult to understand. Constant attention and concentration takes a lot of energy. Energy loss is described as a new disability that one has to consider.

Prioritizing, preparation and planning are key strategies to balance use of energy, and to handle the uncertainty that is part of daily life. Informants tell how they prepare for conversation topics that may arise, memorize the map of rooms before they go for a meeting, to be able to keep focus on communication. Often they have a plan B if things do not go as planned.

To balance the energy, it is necessary to prioritize which activities and relations one wants to hold on to. These can be difficult choices, as it relates to meaning and quality of life.

There is no doubt, that life adjustment is a straining and upsetting process to endure. Neither is there any doubt that one creates a new confidence or acceptance in their life. This new inner strength and trust grows from a personal knowledge of how to maintain participation in society and in your life, by means of one's own resources and adequate support. The personal identity is repaired.

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Editor's Note:

Ms. Rönnblom is one of the authors of the book: LIFE ADJUSTMENT and Combined Visual Hearing Disability/Deafblindness – an Internal Process over Time, Published by Nordic Centre for Welfare and Social Issues, November 2011.

[www.nordicwelfare.org](http://www.nordicwelfare.org)

The other authors are Ann-Christine Gullacksen, Lena Göransson, Anny Koppen and Anette Rud Jørgensen

## **Enabling learning through sensory development in children who are deafblind**

**Plenary presentation, XV Dbl World Conference, Sao Paulo Brazil, September 27, 2011**

In most of Asia, children with disabilities far outnumber medical and rehabilitation professionals, and scattered as they are, largely in rural areas, many never receive appropriate clinical sensory assessments or interventions or may receive them very late in life. Often, as a rehabilitation professional, we may see a child and family for the first time and have just this one chance to make meaningful suggestions that could improve the quality of the child's life. All these pressures has led to a very pragmatic approach in rehabilitation to sensory assessment and interventions, with the priority on understanding how the child experiences and interacts with the world and using this as the basis of an intervention plan. Rather than focussing on the specifics of the sensory impairment, we look at the child's access to experiences and identify the best ways in which to enable that access. Rather than looking at the senses in isolation, we pay great attention to the pairing of senses and their relationship with the development of basic concepts.

### **Our senses and learning**

In the first years of our life, we learn certain key concepts that lay the foundation of learning through the rest of our lives. As babies, we learn about ourselves – our bodies and how they work. In the process of learning about ourselves, we also learn a very important concept; that we, small as we are, can impact the world.

Over the first months of life, we begin to learn about things, people, emotions, places and events. We acquire concepts not by just receiving sensations, but by interacting actively with the world. In acquiring each of these concepts, we rely on one or two of our senses as the leading sense and the other or others are the backup or supporting senses. Particularly in early development, this is important as the infant is only just developing motor capacity and finessing their sensory abilities. Having the most effective sense accessible and available at the right time is therefore very important.

Vision and Touch are particularly important early senses. Vision and Touch, with the support of movement, enable active interaction and active communication with the world. We can reach out and make choices with our eyes and with our hands about who we want to communicate with and to express ourselves without words. This allows self-initiated, positive, successful, and meaningful communication and interactions to take place very early in a child's life. Vision helps the infant cause the world to engage and interact with them. Very early, the baby learns the joy of pulling attention, pushing interaction and each success develops an internal understanding of their own capacity and the desire for communication with people.

When a baby is captured by a sound, a colour, or a movement and reaches out and can feel it, she adds new information to what she got through her vision and begins to understand, that things perceived through the other senses actually have substance. Through this thorough and repeated exploration, the infant begins to understand the nature of things around her, including people and spaces. Only our hands gives us full access to detailed exploration, cementing the visual understanding with an experience of shape, size, texture, function... all of which come together to understand what was seen.

Growing motor maturation allows this understanding of things and spaces reach beyond the arms of the child and to extend experiences to include things in the larger world hinted at by other sensory systems – smells, sounds – all these come from somewhere and something and this pairing of senses allows the child to understand better, to explore and confirm this growing understanding about the world. As each sense captures different information of the same thing or event, using the senses together in experiencing is also a key ability in the development of strong and clear concepts.

For many children, it is not just the impairment of the sense, but other issues, like body tone or sensory tolerance, that make a sense available consistently. A child with cerebral palsy sitting quietly in class may be able to use his vision to watch his classmates as they speak, but when it is his turn, his excitement increases his tone and pulls his head and eyes away so he will not see the expressions or body language in how his classmates respond. With the majority of the children on our case load now including children with complex sensory and motor impairment, it becomes essential to think of these things as we assess the sensory and motor capacity of our children. After all, as rehabilitation workers, our fundamental role is to promote learning and development and to intervene so that children may utilize their sensory and motor capacity to achieve their potential in all areas of life. Assessment of sensory functioning needs to look critically at the availability of the senses to the child in acquiring basic concepts and participating in activities and life.

To impact the world most effectively, we need our active senses – visual, haptic, and some ability to move; the best information about our body, comes from the proprioceptive, kinesthetic, haptic and visual senses; about things from visual and haptic senses; about people and communication: visual, auditory, haptic; information about spaces and environments: visual, haptic, auditory and by moving ourselves and information about events, visual and auditory senses.

When we see particular combinations of senses impaired, we know that those particular concepts will require us, the facilitators, to find ways to enable the development of that concept. When we see particular combinations of senses impaired, priorities for intervention, including sensory training should become immediately apparent. When we focus our training goals on the larger outcome – the development of learning and the interaction with people, things and spaces – we can be assured that we are improving the child’s quality of participation in life. More and more, in our work, we meet children where impairment affects so many systems and is so severe that identifying long term goals and establishing priorities for sensory training is challenging. This approach has helped us stay focused on meaningful outcomes and importantly, to ensure that the little changes we are able to bring about in sensory functioning have an immediate impact on the child’s life and learning.

## **Case study**

When Neil came to us at 6 months, he had bilateral optic nerve atrophy, severe spastic cerebral palsy and repeated ear infections that left him with limited attention or response to sounds. It would have been easy to pick one goal in each area and “stimulate” all senses. However, when we did our assessment, we viewed his particular combination of impairment as a developmental emergency – if we could not improve his access to the world, how would he learn?

Rather than pick everything or only address hearing, his most “fixable” sense, we thought carefully about what would give him meaningful access to the experiences that would enable the development of basic and key concepts. When we looked at each concept area, we found that with his available sensory capacity, we would expect him to have poor awareness of self, things, people, places and events and importantly, he had no reasonable alternate way of impacting the world. His hearing was important, but supporting hearing alone would change little in his map of access to concept development.

Working to link his visual and haptic system became imperative. While addressing his ear infections, we began, right from the beginning, to create situations where movement toward something brought him something he could see and looking toward something brought an interaction with a person or object. We planned specific interventions like this to help build ability in each concept area.

By 14 months, we saw he consistently looked toward a reflective object in a lit room and tried to move his head or arms toward anything or person that caught his attention. More than the improvement in visual capacity from seeing lit things in a dark room to seeing them in a bright room, we were thrilled to see this emergence of a sense of his own capacity – Neil was acting on his world.

When we review his progress in access to the key concepts, we can see his interactions are more effective – small changes, still inadequate, but progress all the

same. We see immediately the areas of no or little impact and this map makes it easy for all of us to select goals, activities and further and presented this way, we can see the next steps. Over the next couple of months, we focus on building relationships and drawing attention to more than the voice for recognition of people – we use symbols for touch, we place very different people in front of him, his soft plump mother and his skinny teacher, their forms highlighted by the light of the window and ask him often to choose the one he wants to play with or to give him his lunch. When he looks at the person, we ask him to lean, to turn his head or move his hand toward the person chosen.

Neil is asked to tell us with whom he wants to work by using symbols. We present symbols differing in texture, form, colour, and size – things that we think he will perceive most easily with touch or vision or both. We leave it to him to indicate his choice anyway he wants, but when he touches the symbol, we ask him to look toward his choice to help us be sure we understood. We work to develop his attention to objects, stress the value of confirmation both for receiving and giving information and constantly give him a reason to touch and see.

Using symbols, Neil tells us with whom he wants to work. He touches the symbol and confirms by looking.

## Conclusion

At age five, Neil continues to have significant sensory and motor impairment. Yet, keeping the sensory intervention focused steadily on accessing basic concepts has meant that he uses what little he has, very well. Yes, his hearing improved, but alone it would have done little to improve his acquisition of early learning.

In the video of a morning session in class, you see his friend complaining loudly and Neil has lifted his head to watch her highlighted against the window. Unable to maintain his position, he drops his head, but lifts it again to watch while he listens. As he lifts his head, his friend snatches his toy from in front of him, and catching this movement, (seeing it? feeling it?) he drops his head again to quickly confirm it is indeed gone.

Vision, hearing and touch help Neil in communication and even though his vision is not much better than before, he uses it quite well to confirm information from other senses and to get information about his social environment.

His actual visual improvement from age 6 months when he first came, to 5 years, is simply that he can now see gross form, whereas, before he responded inconsistently to light. His hands are still fisted, reach still needs upper arm support, but he uses vision to support touch and touch to support vision and hearing.

His use of vision in learning has moved from simple awareness of a stimulus to active searching and he now has a variety of ways to get information and to interact with people and the world. With his severe motor impairment, touch is not efficient, yet in combination with other systems is an important source of information and way of interaction. He uses it to confirm what he hears or glimpses with his vision, he moves his body to try and feel around him, but most importantly, he is able to use the few things he can discern – texture, hardness, impression of size – to develop an impressive symbol based vocabulary.

I chose to talk of Neil, because it is not a fairy tale ending. At five, Neil is not able to do a lot in the major areas of life, but, he knows inside himself that he can act on the world, he has ways to interact with it and a desire and ways to communicate. I believe that through our intervention choices we have drawn back the curtain and he can now move on to a lifetime of opportunities.

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## After Laura and Helen:

**The Changing Face of the School-Age Deafblind Population in the USA and at Perkins, and Its Impact on Education.**

**Barbara B. Mason (Education Director) and Martha M. Majors (Assistant Education Director) Deafblind Program, Perkins School for the Blind, Watertown, Mass. USA. Workshop presented at the XV Dbl World Conference, Sao Paulo, September 2011.**

Since the education of Laura Bridgman in 1837 and Helen Keller in 1886, there have been significant changes in the deafblind population in the USA. The impact of the rubella epidemic beginning in the early 1960's caused a huge shift in the education of students who were deafblind. This trend continued for years, until most of the rubella population left the education system and transitioned to adult services. During the past twenty years, there have been other significant changes in the population of students who are deafblind, and these changes have had tremendous impact on the delivery of educational services. These changes have included an increase in the number of children born with CHARGE syndrome, Cortical Vision Impairment (CVI) and multiple congenital anomalies. This changing population of students has resulted in new challenges and implications for education. This article will look at those changes from two different perspectives:

### The National Perspective

Prior to the rubella epidemic starting in the early 1960's and continuing through to 1992, there were few national documented census records of persons who are deafblind. This was before there were national efforts to document the incidence and etiology of deafblindness throughout the United States.

Marianne Riggio was able to document some of these changes in deafblindness etiology by using census figures from the New England Center Deafblind Program (Riggio, 1992). While these are regional census figures, they do represent trends in etiology happening nationwide. Please refer to Chart 1.



Chart 1 shows a significant drop in rubella as the cause of deafblindness from 61% in the 22 – 27 year old population to 4% in the younger 0 – 15 children. In contrast there was a significant increase in multiple congenital abnormalities in the younger children aged birth to 15 years.

For the past twenty-five years, there has been a more accurate and comprehensive national census on deafblindness. Currently the National Consortium on Deaf-Blindness (NCDBN) collects information on an annual basis to provide a census of children and youth who are deafblind from ages 0 – 22. The most recent census reported is for the year 2011 in a paper published in December 2011 (National Consortium on Deaf-Blindness, 2011). It identifies 9,387 children and youth with deafblindness in the child count for the year 2011.

As part of the census, information is gathered on gender, etiology, documented hearing and visual loss, Cortical Vision Impairment, Auditory Processing Disorder and neuropathy, additional disabilities, ethnicity, as well as living and educational settings. Chart 2 documents the National Deafblind Count (2011) according to the primary etiologies.

Of significant note in Chart 2 is that rubella as a cause of deafblindness has continued to decline while CHARGE Syndrome has continued to increase. In fact according to this chart, rubella (70) along with encephalitis (72) account for the smallest etiologies reported.

It should be pointed out that many of the identified etiologies listed above tend to cause one or more additional disabilities in addition to sensory losses.

## Chart 2. National Deafblind Count (2011) according to primary etiologies

PRIMARY IDENTIFIED ETIOLOGY	
<b>Hereditary Syndromes/Disorders</b>	
CHARGE association	824
Usher Syndrome (I,II,III)	263
Down syndrome (Trisomy 21 syndrome)	226
OTHER: Hereditary/ Syndrome Disorders	2375
<b>Pre-Natal/Congenital Complications</b>	
Cytomegalo-virus (CMV)	332
Microcephaly	275
Hydrocephaly	248
Congenital Rubella	72
OTHER: Pre-Natal/ Congenital Complications	652
<b>Post-Natal/ Non-Congenital</b>	

Asphyxia	235
Severe Head Injury	193
Meningitis	188
Encephalitis	70
OTHER: Post-Natal/ Non-Congenital	590
<b>Complication of Prematurity</b>	<b>1108</b>
<b>No Determination of Etiology</b>	<b>1736</b>
<i>National Consortium on Deaf-Blindness, 2012</i>	

### Perkins Deafblind Program Perspective

The second perspective focuses on the changes in the population being educated in the Deafblind Program at Perkins School for the Blind, and how the educational system has adjusted to meet their needs. This includes the challenge of maintaining a clear and focused mission of who we serve, while adjusting to the overall educational needs of a diverse population of children who are deafblind.

Chart 3 demonstrates the change over the period 1974-2011 in the makeup of the student population being educated in the Perkins Deafblind Program. Rubella decreased from being the primary cause of deafblindness in 1974 to be generally absent in 2011. On the other hand, children with CHARGE and other syndromes as well as with unknown causes have tended to increase in more recent years according to Perkins records.

Clearly in the 1960s and 1970s at the height of the rubella pandemic, congenital rubella syndrome was the focus for the education of students in the Deafblind Program at Perkins.

Since that period, there has been an increase in the identification and diagnosis of children with CHARGE Syndrome in the United States and elsewhere. This has resulted in a corresponding increase in the number of students diagnosed with CHARGE attending the Deafblind Program at Perkins. At this writing there are 26 students enrolled in the Deafblind Program at Perkins who are diagnosed with CHARGE Syndrome.

Children with CHARGE who have been admitted to the Deafblind Program demonstrate cognitive development ranges from developmentally delayed (mild to moderate) to intellectually challenged (severe to profound) to normal. See Chart 4 which shows the distribution of cognitive Levels of students attending Perkins Deafblind Program in 2003 and 2011. This supports the national profile of the overall ability and potential of the child with CHARGE.

### Chart 3.

#### Change in distribution of deafblindness etiologies of the students in the Perkins Deafblind Program, 1974-2011

	Rubella	Charge	Other	Unknown
1974	55%	0%	19%	14%
2001	6%	25%	30%	11%
2011	0%	45%	25%	12%

Records (confirmed in Chart 3) indicate that more children continue to be born with rare syndromes and many are being educated at Perkins. While these children demonstrate more complex issues, the overall range of their cognitive abilities remains relatively similar. This is generally confirmed in Chart 4, which indicates that the measured cognitive levels of the students are remarkably similar between 2003 and 2011.

The communication needs of these students continue to be a major focus in our Program. In the past with the rubella children, sign language and speech were the foundation when learning to communicate. The current students require a wider definition of total communication that includes sign language, simple sign speech, objects, symbols, line drawings, photos, print, Braille, etc. To compliment this, there is and increased use of technology that includes access to voice output devices, computers, iPads, etc. Various types of communication boards with topics are also frequently used in many classrooms. As students participate or integrate more in the community, it is essential for them to communicate with non-signing adults. Consequently, the use of topic boards has been a major component of our community-based instruction.

### Chart 4

#### Distribution of cognitive Levels of students attending Perkins Deafblind Program in 2003 and 2011

2003	2011
Developmentally delayed 3 – 9 years = 32%	Developmentally delayed 3 – 9 years = 37%
Moderate – Severe = 25%	Moderate – Severe = 30%
Severe – Profound = 41%	Severe – Profound = 33%

More physical challenges have created a need for additional physical therapists and more equipment such as wheelchairs, walkers, braces, etc. These students require more physical therapy (PT) services and accessible environments such as doorways and walkways, as well as added facilities such as sinks, toilets, and tabletops. This increase in physical challenges requires the need to develop additional fine motor skills, such as use of hands to sign, and access to communication devices (as appropriate). The sensory needs of several of these students require Occupational Therapy staff who are knowledgeable in the area of sensory integration issues and who possess the ability to design highly individualized programs for each of the students.

In addition to the increase in the number of children with rare syndromes in our Deafblind student population, there has also been an increase (over the last 15 years) of children diagnosed with Cortical Visual Impairment combined with a hearing loss. This has created a need for staff to be further trained in the area of CVI and in the implementation of the use of specific materials for a student with this condition.

Across the country many students are having cochlear implants (CI). This is a major contrast to the years when students with rubella wore body aids and used FM units. Cochlear implants have required the staff to: better understand how children hear sound; help their students to wear their CI to better tolerate different sounds, especially in noisy environments. This has meant that teachers are required to learn new skills and receive additional training in order to be more successful in assessing their students.

### Curriculum Challenges

As a result of the wide range of cognitive abilities of the students, there has been a need to further adapt the teaching curriculum. This includes the need to more clearly define the levels of curriculum from preschool through vocational; better develop access to the curriculum using specific materials (i.e. ensuring their durability and safety) for students with physical challenges, CVI challenges and behavioral issues. As we adapt the curriculum, we need to keep in mind the need for staff to use the tried and true “best practice” teaching strategies designed for the rubella students who were deafblind. Those strategies were effective for many years and they are still the foundation in every classroom designed for these students. Additionally, more teachers are collaborating with teachers of the visually impaired to support compensatory strategies including Braille instruction. The Expanded Core Curriculum is a part of every student’s program.

### Medical Challenges

Approximately five percent of the students now have 1:1 nurses working with them in the classroom. The teaching staff have adapted to having a medical person working with them side-by-side. The teacher and the nurse understand each other’s role such that together they offer the more medically fragile child who is deafblind an opportunity to have a high quality education, in spite of their medical needs.

In summary, the current population requires access to a broader number of specialists, staff who are better trained to meet the complex needs of each student, and more support for families as well as parent education.

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## **Black and White Multisensory Rooms**

### **Educational Rooms used with Deafblind and Multisensory Impaired Students**

by Christine Sauvé Guindon

Two multisensory rooms are used in some schools in the Province of Ontario with students who are Deafblind and with those who are multisensory impaired. The 'White Room', utilizing the Snoezelen<sup>1</sup> philosophy, uses a non-directive approach where exploration and relaxation is fostered. The 'Black Room' has different motives, where a more directive approach with goals and outcomes can be assessed. This article will present the educational possibilities of these two distinctive yet complementary rooms.

The content of this paper is based on the Qualification Additionnelle en Surdicécité (Additional Qualifications Course on Deafblindness) that is offered to teachers at the Faculty of Education, University of Ottawa, Sauvé Guindon, Christine (2003 – 2012).

#### The White Room –

A setting for exploration and observation

The Snoezelen 'White Room' is an environment where Deafblind and multisensory impaired students have the opportunity to explore and simply 'be'. It is a privileged environment that uses a non-directional approach where the students are able to enjoy a multisensory setting using their senses of touch, residual vision, residual hearing, smell, as well as their vestibular senses and body proprioceptors. The White Room offers a safe and peaceful environment where a child can experience music, lights, vibrations and various textures, Biblio-thème no 6, 2010. It is a motivational setting that encourages choice making hence promoting learning. It is usually here that the child first has a control over his or her environment. This can

lead to reduced levels of anxiety and a lessening of their defence mechanisms caused by enhanced sensory stimuli.

It is in the White Room that teachers observe their students. They see the student's true potential; observing their making choices and what senses the students utilise as well as how other senses could be further developed; observing what relaxes or stimulates the child, including their likes and dislikes, etc.

Once a student knows a Snoezelen room and feels at ease in it, he will interact spaciouly using their vestibular senses; moving around, despite sensory deprivations or physical limitations. Feeling at ease, the student will crawl or roll towards a stimulus; possibly activating a switch, or choosing to rock in a chair. A child with very limited functional vision can suddenly react to lights. Having control over their environment, the student can make deliberate choices. In summary, the White Room is an environment where the potential of the student can emerge and bloom.

For example, Marisol seems to enjoy illuminated objects in a darkened room. The fibre optic lights captivate her and she appears to truly enjoy playing with them. By simply paying attention and observing, a few of her capabilities become evident, such as: visually tracking and manipulating lighted objects in the dark; integrating her vision and touch; ability to problem solve, anticipate and communicate, etc. She demonstrates spatial awareness and shows the capacity to make deliberate choices in the room.

#### The Black Room – A setting for teaching

The Black Room is an environment conducive to teaching and learning. Here, the teacher directs the activities. It is an interactive space that enables training for different skills. It is a controlled environment; an ideal setting to work on specific educational goals described in the student's Individual Educational Plan (IEP).

This interactive multisensory environment characterized by lights, sounds of different frequencies originating from various musical instruments, is a valuable educational setting that promotes discovery and learning. The goal here is to make the setting purposeful and meaningful for the learner. In summary, it is a space where one can consolidate knowledge.

For example, if we have a student that we observe in the White Room who can visually track, we should be able to replicate this activity in a formal and controlled setting. The Black Room is an important setting where we can solicit one sense at a time without distractions from other noises or distractions.

In this room the student is accompanied by an adult who directs activities which vary according to the needs of the individual student and their specific goals. It is here that one can concentrate and work on the following areas: vision and hearing, sensory integration, communication, cause and effect (action/reaction goals), bonding and formal curriculum, etc.

In a Black Room, one will usually find:

- a room painted black or in a colour that absorbs the light;
- a sound proofed room;
- equipment that will permit visual and auditory stimulation;

- an area with switches and interactive toys to work with action – reaction goals;
- an area to promote fine and gross motor skills;
- other equipment (swings, ballpools, mats, bean bags, etc.) positioned to ensure comfort and allowing for different stimulations

To ensure success of the activities in the Black room, the teacher should: know their student very well including their goals; understand how to work the various pieces of equipment of the room; ensure the child's comfort, and carefully record their observations.

### How to set goals?

Remember that little girl, Marisol? With each visit in the Snoezelen room, I was continually watching and recording my observations. Afterwards, I would try to make links between what I had observed to create an educational plan perfectly suited for her, and set goals to be worked on in the Black Room. By paying close attention, individualized goals can be set in many key areas such as: residual vision, residual hearing, cause and effect, communication, fine and gross motor, orientation and mobility, and formal curriculum goals.

There needs to be a link between the informal education done in the White Room to the formal education that can be done in the Black Room. The IEP should reflect these modifications and include adaptations and strategies to ensure the student's success. The IEP should make SENSE.

I often say to adults who work with kids with multisensory needs: "What will be the reward? What is the motivator?" What are you doing with your students that will motivate them? What incites them or drives them to want to succeed? Activities we choose to do with our students must be "purposeful and meaningful!"

It was through the advice from John McInnes (McInnes & Treffry 1982) that I learned that it all has to start with the interest shown by the child. Being that the Snoezelen room is a 'reactive environment', it is the students' who take the lead. It is the students who decide what they want to do, what to try and what they will explore; it is all on their terms. What they show us they can do by their own conscious effort in this room is what should be transferred to the Black Room. This is what we can do to achieve their true potential.

When new abilities are reached, the next logical step is that we need to work to transfer these newly acquired abilities out of the White and Black rooms into the formal classroom. The student should then benefit from these new skills and put them to good use in other settings. The ultimate goal will be to transfer these same skills for better integration in their home and community.

### Conclusion

Learning is a cycle. The more you know, the more knowledge you can acquire. New goals can be elaborated; leading us to plan for new expectations, new challenges... one goal at a time, building on what was learned. The circle of knowledge is continuously evolving! My wish is for my students to have the opportunity to develop, grow, flourish, and strive. The multisensory rooms (black and white) are perfect settings to achieve this. In these rooms, one sets goals that are worthy of their

interests, their skills, and their physical and intellectual abilities. To witness these children making so much progress through this process is incredibly exciting and fulfilling!

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## **Kentalis Deafblindness Centre of Excellence in the Netherlands reports on its First National Conference**

### **Kenniscentrum Doofblindheid**

Shared knowledge, share your knowledge

Over the last few decades various initiatives have been launched by Dutch interest groups and health organisations, aimed at improving services for people with deafblindness. This collaboration has produced a lot of positive developments in our country, but we are not there yet! A huge need for better collaboration and sharing still is felt among all people involved. In order to safeguard the future with regard to



the sharing and development of expertise, Kentalis is using its own centre of excellence as the binding factor both in The Netherlands and abroad. On November 8, 2012, Kentalis Centre of Excellence organised its first national conference titled “Afhankelijke Onafhankelijkheid or Independent Dependency”<sup>1</sup>. Together with 200 enthusiastic colleagues we explored the delicate balance between sustaining a persons’ independency, while their dependency on other people in their daily life is increasing. In order to provide for good professional support and guidance there is a need for greater understanding of what a person with deafblindness may go through living in these two realities of independence and dependence.

Marleen Janssen, professor of deafblindness at Groningen University, fascinated the public with suggestions on how to explore new ways to improve the communication with people with deafblindness. But the very moving story of Femke Krijger, a working mother of three children coping with her progressive deafblindness, insisting on focussing on the dialogue, again was an eye-opener for the professionals. Together with the parallel sessions held in the afternoon it was a stimulating knowledge event. We are looking forward to contributing to the international conference on acquired deafblindness (ADBN) in Lund, Sweden, November 7-10, 2012.

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## **“Despite my Conditions, I am Human”**

This is the title of a Photo Exhibition, produced by the National Resource Centre on Disability, Assistive Technology and Social Psychiatry, a section of The National Board of Social Services in Denmark. The Resource Centre has an office in Aalborg where the main focus is to collect, adapt, develop and spread knowledge on congenital deafblindness.

Very often we find ourselves using a lot of words trying to explain this rare and complex disability and when you have told the same story a million times, it is time to try another way of reaching your audience.

Therefore we decided to try to communicate without words. We invited a professional photographer into ‘our world’ and asked if he was willing to spend a week or two in different environments where people with congenital deafblindness live, go to school, work and spend their free-time.

Fortunately the photographer, Magnus Moeller, was enthused about this project and during some weeks in 2011 he visited families and care and educational services

which enabled him to make an honest and down-to-earth portrait of this special group of people.

With his exhibition 'Despite my Conditions, I am Human', Magnus Moeller tries to provide insight into this world with thought provoking results.

With his camera he draws our attention to the isolation that the dual sensory loss has created for these individuals. He also catches the intimacy, the attachment and the joy that people with congenital deafblindness experience when they are met by people who really want to interact with them. And he portrays the spectacular way that deafblind people experience the world, through their dominant tactile sense. This exhibition consisting of 23 large photographs (each one measuring 70 x 100 cm) is now on tour in Denmark. There has been great public interest in showing this, especially at various colleges and public offices throughout the country. The exhibition is shown for one month at each location and is now booked until November 2013. It is anticipated that this exhibit will be displayed during the Dbl European Conference in Lille, France, August 2013.

According to the response we have received until now, the exhibit has created much favourable discussion and reflection. Hopefully through this exhibit, more people will become more aware of the fact that congenital deafblindness actually exists and that there is a group of people among us who experience the world in a different way than most of us. And that this way of living your life, despite having many challenges also has plenty of good qualities.

Marianne Disch

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## **Sense UK announces the publication of a booklet and video titled 'Reflective Practice'**

'Developing good working practice using a framework of seven principles and video analysis with people who have sensory loss and limited communication skills', was a research project conducted by Asuncion Snow and Anne Telling, and was presented at the XV Deafblind International World Conference in Brazil. The outcome of this project was to publish a booklet supported by a DVD with video examples.

The booklet contains theoretical background information on seven key questions for developing good practice that form the framework for reflective practice, allowing the practitioner to consider the rationales behind the techniques being taught. More crucially, it enables them to adapt their practice to suit the person's needs, encouraging a person-led approach whilst supporting a 'shared experience', thus

improving the quality of day-to-day interactions. The DVD contains illustrations of some of the seven questions for analysis.

The seven questions relate to seven key areas of communication development, and have evolved from the experiences of the research team who have worked over many years with people with both congenital and acquired deafblindness.

This booklet will be of relevance to professionals, learning assistants, support workers and carers, whilst parents and family members and friends will also benefit.

The booklet will be ready in January 2013 but if you would like to find out more please contact:

Sense Information & Advice

Service: [info@sense.org.uk](mailto:info@sense.org.uk);

Asuncion Snow: [asun.snow@sense.org.uk](mailto:asun.snow@sense.org.uk)

## **Country News**

### **Argentina**

#### **An Independent Living Residential Service in an Argentinian Community**

**Paula Rubiolo, Aurea Soza and Graciela Ferioli, Perkins International – Latin America**

##### **Introduction**

This paper describes the successful process undertaken by a group of families of young adults with deafblindness and multiple disabilities living in Cordoba, Argentina to enable their disabled children to have a more complete and independent life.

The legal background for this project is based upon the Convention on the Rights of Person with Disabilities, its purpose being to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Furthermore in this context, the families intention was to ensure that their children have a complete and independent life through consideration for such rights as communication (accessibility to language and technology), social and cultural inclusion (education and social integration) and universal design (accessible accommodations ), etc

##### **Needs and Expectations**

The families had determined that in their particular community, the availability of educational, health, rehabilitation and therapeutic services had prepared their children reasonably well for transition into adult life. With these local services available it seemed like the next reasonable step was to have a residential program where the young adults with deafblindness and multiple disabilities could live their lives independently in the community.

The families believed that their decision to have their children live outside of the nuclear family with the support of a collaborative team would help them develop a positive self image and more empowerment.

All involved in this program expected that this venture would be effective since it would take into account the wishes of the young individuals with deafblindness, their families, and would involve support from professionals, community members and other significant people and organizations involved in the young person's life.

### Developing a proposal

This project also arose from expressions of need identified by Perkins International that this type of program has real value for these young disabled persons. It is based upon Perkins experience with support services for young people with deafblindness and multiple disabilities throughout Latin America and in Argentina in particular.

As a consequence of the expressed need by families and their positive expectation of success from such a project, a group of professionals and parent leaders from the region with experience in the field developed a proposal describing a set of objectives and principles to guide the implementation of a residential service as a further part of Transition to Adult Life.

After discussing this proposal with the authorities from the Government of the Province of Cordoba, Argentina, an agreement was subsequently signed between Perkins International and the Ministry of Social Development of Cordoba Province, Argentina permitting a coordinated development to take place which would satisfy the rights of this population. This collaboration was actively supported by various government agencies, FOAL (ONCE Foundation for Latin America) and Perkins International. The result of this planning was the implementation of residential setting for young people/adults with deafblindness and multiple disabilities.

### Guidelines for development

Two fundamental tenets were recognized as integral to this project: 1) that working cooperatively with families based on the child's and family needs was critical, and 2) that there needed to be a collaborative approach with family members to train staff. Collaboration between school and family is considered indispensable to foster independence and self-determination for each young adult.

In Argentina, it should be recognized that many determinants influence family lifestyles and behavior towards disabilities, not least of which include geographical, social, economic and religious influences. For these reasons when designing the best housing service for these young adults, it was necessary to consider that each resident brings his or her own values, customs and culture to the residence. In addition, each resident has his or her own needs, strengths, resources and interests that must be considered when planning their life in a new home outside their family home.

Parents need to maintain their identity as parents, as well as participating members of their community. There is much stress observed in these parents due to the physical and mental fatigue from having the responsibility of caring for their children 24 hours a day year after year. This situation causes many parents to lose sight of

their own individual needs. This residential service will allow family members, parents in particular, to recover their personal life activities and friendships; ultimately allowing them to feel individuals again with their own power of self-determination.

### Project Implementation

Through the process of planning, implementing, and maintaining this residential program, the organizers visualized an operation where the guiding principles of the service would attempt to achieve planned results based on the needs of users, yet recognize organizational and economic realities. This led to developing an organizational structure with the definition of various roles and responsibilities for staff operating the facility. An executive committee was appointed to lead the decision making process.

This residential service is operated under Argentinian Law N 26378 and in accordance with the United Nations Convention on the Rights of Persons with Disabilities (2008). The definition and regulatory framework for this residence is based on this legislation which recognizes that these young adults are citizens with rights respecting self-determination and requiring the appropriate adaptations to contribute to their full social inclusion.

Through this philosophical and legal framework, the collaborative group designed the residential service model group home centered on each resident's goal of having an independent life experience. This model is considered successful as the result of providing various support personnel who assist with access to communication, physical resources, and technological adaptations that enhance each individual's accessibility needs.

In summary, this experience developing the group home model in Cordoba has had numerous positive outcomes, including: an opportunity for these people with deafblindness and multiple disabilities to live a dignified life despite their individual limitations; families were given the opportunity to recover their individual identities; a diverse team of staff members was developed, and within the community there was created an increased level of awareness and social responsibility.

For more information, contact Graciela Ferioli ([hperkins@fibertel.com.ar](mailto:hperkins@fibertel.com.ar)), Aurea Maria Soza ([aureasoza@hotmail.com](mailto:aureasoza@hotmail.com)) or Paula Rubiola ([paulawebperkins@gmail.com](mailto:paulawebperkins@gmail.com))

Editors Note: Article originally written in Spanish and translated into English by Paula Rubiola. Thanks to Wynn Cherry for helping the editor to finalize the English translation.

## **Australia**

ADBC has been involved in writing submissions for the Draft Report Communicating with People with a Disability National Guidelines for Emergency Managers, National Disability Services paper into Sensory Disability and the National Disability Insurance Scheme a Response to Eligibility & Reasonable and Necessary Support. Full versions of these submissions can be viewed at

[www.deafblind.org.au/reports.asp](http://www.deafblind.org.au/reports.asp)

Current News Sheet, Beacon Magazine and Special Edition News Sheet for DeafBlind Awareness Week can be viewed at

<http://www.deafblind.org.au/newsletter.asp>

### National DeafBlindness Conference Sydney 2013

The 2013 Australian National Deafblindness Conference will be held in Sydney from 4th – 7th October 2013. The Foresight Foundation has agreed to convene the event in collaboration with other the Deafblind Association of NSW, Deaf Society, NSW/ACT Guide Dogs' Association, Vision Australia, Royal Institute for Deaf and Blind Children, ABLE Australia and a group of passionate individual supporters. Check out: [forsight@bigpond.com](mailto:forsight@bigpond.com) for more information.

### Let's Connect

We are delighted to announce that the V.V. Marshman Charitable Trust has agreed to fund a three year extension to the Let's Connect project. The first three years involved deafblind awareness training being run in each State and assertiveness training for people with deafblindness run in all States but South Australia and Tasmania due to insufficient expressions of interest. In March 2012 a National meeting was held with representatives from Vic, NSW, WA, Qld, and SA. At this meeting it was agreed that it was important to seek funding to continue to meet to work together to improve services for people with deafblindness in Australia.

V. V. Marshman trustees are concerned with the health and welfare of rural Australians so the second phase of the project has rural emphasis.

For more information, contact:

[meredith.prain@ableaustralia.org.au](mailto:meredith.prain@ableaustralia.org.au)

(Editors remark: For a description of the work plan for the next phase of the project check out Meredith Prain's report in this edition of Dbl Review.)

### Able Australia

Deafblind services have been actively applying for various short and long term funding to increase the level of support to the deafblind community. While many of the people with deafblindness are on waiting list for funding, Able Australia has organised a number of activities to reduce the isolation and boredom.

One of the activities will be "able day in the sky". This is a life time experience for many of the people who have hearing and vision losses. This will be held on 8th of December, 2012 at the Moorabbin airport along with a lunch and a visit from North Pole. The day has been organised with the support of Concept Coordinators by Jan Flude and Antoinette Puzzolo.

Another popular activity is the annual National Deafblind Camp 9 to 11 March at the Phillip Island Adventure Resort. The theme is Mexican with all of the trimmings!! The Recreation program continues to attract a large number of people with deafblindness. For more information about recreation program, please contact Fiona Goldab at [fiona.goldab@ableaustralia.org.au](mailto:fiona.goldab@ableaustralia.org.au)

Three resource guide kits (DVDs) are being made with focus on Deafblind communication techniques, Interpreting for people who are deafblind, Deafblindness and the elderly.

These kits are aimed at staff, educators, allied health professionals, TAFES, universities, interpreters, Auslan students, case managers and many more. For more information, contact: [carla.anderson@ableaustralia.org.au](mailto:carla.anderson@ableaustralia.org.au)

### Ablelink

Ablelink has secured two small grants this year called "Peer to Peer training" and "Low vision and Braille access to mobile devices". We have been able to buy a range of mobile devices including ipads, iphones and Braille displays to facilitate this training. Some deafblind trainers are teaching braille literacy and braille access to iphone and ipads. Other deafblind trainers are teaching how to access ipads and iphone using magnification.

The braille trainers have attended workshops and are preparing their training materials and finding ways to improve communication, cater for different learning styles and maintain motivation. This is a huge undertaking and involves a lot of support. This project is the first of its kind in Australia and it is addressing a real need in the deafblind community. More information, [claire.tellefson@ableaustralia.org.au](mailto:claire.tellefson@ableaustralia.org.au)  
Senses Foundation, Western Australia

### Father Cyril Axelrod

Saturday the 25th of August, 2012 was a special day at Senses Foundation with Deafblind priest Father Cyril visiting us to share his life story. Father Axelrod is a Redemptorist priest who was born Deaf and was diagnosed with progressive blindness in his forties due to Ushers Syndrome. He was one of the first Deaf persons in the world to train to become a Catholic priest. He currently lives in London and helps the Deaf and Visually Impaired population in the Camden Town area.

"Most people's view of deafblindness is that it is unspeakable, unthinkable and unimaginable. For me it has become a new way of life and one that has offered a new direction...It has become the best teacher in my life."Fr. Cyril Axelrod  
Fr. Cyril uses himself as an example to those he interacts with, showing them that disabilities do not have to be barriers for people to being effective and equal members of society. "I think that out of all the projects I have, the most important one is myself as a model", he explained. By allowing others to see that his deafness and blindness were not hindrances to developing his unique skills and talents, he could become a living example of hope for them.

Father Cyril spent his time in Perth as a guest of the Emmanuel Centre, a Catholic self-help centre for people with disabilities and addressed numerous schools, disability services and Deaf communities in his role as bridge-maker. He hopes that one day he will have the opportunity to reside in Western Australia to work with and advocate for people who are Deafblind. Thirty three people attended the day and were enthralled and inspired by Father Axelrod's story and philosophies "Regardless of whether we are hearing or Deaf or have any other disability, we are all equal and must have the same rights to education and work. We need to understand each other's differences, but not be frightened ... we have to respect one another."

### DrumBeat

On Saturday 7th of July, 2012 the Ushers Syndrome Support Group met to participate in a trial of the Drumbeat program. The Drumbeat program was originally developed to reach young people for whom talk based therapies were confronting. It uses music, drumbeat, rhythm and vibration to provide a sense of connectedness with others, encourages creativity and self-expression, reduces isolation, tension, anxiety and stress. The day was a huge success with fifteen members attending and getting their groove on. We will be repeating the program at the upcoming WA Deafblind Camp and are hopeful to be able to offer to other Senses client groups in the future. Special thanks to Vanessa Trengove from HolyOake for volunteering her time to facilitate this program.

### Sibling Support Program – "SuperSibs"

As part of our ongoing commitment to building stronger families, Senses Foundation hosted a "SuperSibs" Sibling Support Workshop on the 9th of July, 2012. Senses Foundation established "SuperSibs" to support siblings of children with disabilities in 2006. The continuation of this program has been generously supported by PACT Construction in 2012.

Senses Foundation "SuperSibs" seeks to provide siblings of children with disabilities opportunities for peer support and education, the group provides a safe and supportive environment for sibs to share their feelings, concerns, questions and problems. This group creates an atmosphere for positive change and adaptation, reduces sibling's sense of isolation through new friendships and aids the growth of more positive attitudes and understanding toward their siblings. "SuperSibs" offers siblings a broad array of solutions and strategies from which to choose to cope with their own individual challenges living with a sibling who has a disability.

Seventeen siblings attended the "SuperSibs" workshop on the 9th of July; our biggest turn out ever and fantastic to see families embracing the importance of this innovative program. Senses Foundation continues to celebrate and support the unique relationships between siblings and our next "SuperSibs" workshop will be run in the October school holidays.

### Research Projects Underway in Western Australia



A significant donation to Senses Foundation in 2011 from Andrew and Nicola Forrest, of Fortescue Metals Group shares, has made it possible for Senses Foundation to undertake two research projects in the 2012/2013 financial year.

1) A study to identify basic demographic information about the people who are deafblind in Australia

Senses Foundation has commissioned a study using the data from the Survey of Disability, Ageing and Carers (SDAC) conducted by the Australian Bureau of Statistics (ABS) throughout Australia, from April to December 2009. This study will identify:

- The number of individuals with a dual sensory disability of vision across Australia
- The age and gender of these individuals
- The geographical distribution of these individuals, with a specific aim of ascertaining the number of individuals living in rural and remote areas of the country.
- The degree of activity and participation limitations for the target group which will assist in determining the specific service needs of individuals with a dual sensory disability.

In 2007, Senses Foundation commissioned a similar study using data from the 2003 census. The report of that study entitled "Unseen and Unheard" has proven to be a significant and strategic document, justifying much of Senses Foundation's program development and supporting arguments regarding the quantum and needs of people who were deafblind in Western Australia.

2) Identify a tool which would be suitable for screening for Usher Syndrome in Australia

The second study Senses Foundation has commissioned aims to identify a tool which would be suitable for screening for Usher Syndrome in Australia.

Early diagnosis of Usher syndrome is very important. The earlier that parents and school personnel know that a child has Usher syndrome, the sooner that child can begin special educational training programs to manage the loss of hearing and vision. Early diagnosis also allows well informed decisions to be made as to the best communication method for a child who is deaf but who will also lose their sight.

Usher Screening programs are common in America, Canada and parts of Europe with screening manuals and training readily available for teachers and school nurses. However, Australia currently has no screening programs.

Once an appropriate screening tool is identified, Senses Foundation plans to lobby for the introduction of a screening process which dovetails the Newborn Baby's Hearing Screening currently available throughout Western Australia.

## Deafblind Information

Deafblind Information is a web-based resource managed by Senses Foundation for anyone interested in finding out information about deafblindness. Stories of people who are deafblind give the view of people living with deafblindness and we invite others to share their experiences to be added to the website.

Visit Deafblind Information  
[www.deafblindinformation.org.au](http://www.deafblindinformation.org.au)

### Australian Childhood Vision Impairment Register

The Australian Childhood Vision Impairment Register is hosted by the Royal Institute for Deaf and Blind Children and is the first national register of children in Australia with vision impairment. The Register has been collecting data since 2009, and this data is providing important information about the types of eye disease and vision disorders children have and the support they need. The data is also used by service providers and researchers. VI Family Network, the website which hosts the Register can be viewed at [www.vifamilynetwork.org.au](http://www.vifamilynetwork.org.au). The latest findings from this register can be viewed at [www.deafblind.org.au/content-files/ACVIR%20newsletter%20august%202012%20\(2\).pdf](http://www.deafblind.org.au/content-files/ACVIR%20newsletter%20august%202012%20(2).pdf) or if receiving this news sheet in hard copy please go to the reports section of ADBC's website

## **What we've learned from the Let's Connect Project and where it's heading now**

Let's Connect was a project funded by the V. V. Marshman Charitable Trust and coordinated by Able Australia. The project ran for 3 years commencing in June 2009. The project aimed to provide deafblind awareness training to service providers and assertiveness training to people with deafblindness and their families and carers in each State of Australia. The training workshops were held throughout Australia during 2010 and 2011 in the following cities: Melbourne (State of Victoria), Sydney (State of New South Wales), Brisbane (State of Queensland), Hobart (Tasmania), Perth (State of Western Australia), Darwin (Northern Territories) and Adelaide (State of South Australia).

### Deafblind Awareness Training

The Deafblind Awareness Training was divided into two half day sessions, one on working with people with congenital deafblindness which focused on the work done by the Dbl Communication Network and the second on working with people with acquired deafblindness. Attendees, totalling 147 participants, represented a wide range of professional backgrounds and services including allied health therapists, social workers, disability support workers, early intervention teachers, disability employment consultants, orientation and mobility instructors, case managers and teachers.

### Assertiveness Training for People with Deafblindness

Guest speakers were invited to attend the Assertiveness Training for people with deafblindness from State based Equal Opportunity and Anti Discrimination Commissions to discuss legal rights and processes for making complaints as well as representatives from the advocacy organisation Blind Citizen's Australia. A total of

49 deafblind persons participated in the training sessions in Melbourne (8), Sydney (20), Brisbane (8) and Perth (13) .

The cost for interpretation and note taking for people who are deafblind was provided by the project's sponsor (V. V. Marshman Charitable Trust). This was supplemented by in kind support from such organisations around Australia as Able Australia, The Forsight Foundation, Senses Foundation, Deaf Services Queensland, Guide Dogs Tasmania and Kilparrin School.

#### Key learnings from the project

Considerable support is required to ensure people with deafblindness are able to attend and participate in any form of face to face information session. Supports include: communication needs (audio loops, interpreters-sign language and tactile, note takers); appropriate room set up for best communication (lighting, interpreter table set up, etc); assistance with transport; providing print information in alternative formats; providing assistance during breaks, including sighted guide to toilets and assistance with meals.

The cost of interpretation may be quite expensive when running large workshops. For example, at the workshop in Sydney, 7 totally deafblind persons each required 2 tactile interpreters; for those with vision, 2 – platform / visual frame interpreters were required as well as two note-takers. Therefore it is important to budget for the high cost of interpreting when planning such workshops.

#### Future directions

The overwhelming response from people who participated in the workshops was that they were valuable and need to occur more often. As a result representatives with deafblindness, carers and service providers from Western Australia, South Australia, Victoria, New South Wales and Queensland attended a meeting in March 2012 to discuss the next steps. All agreed there was a need to meet more regularly to support each other to promote the needs of people with deafblindness in Australia.

The V. V. Marshman Charitable Trust has agreed to fund the project for a further three years and the project will now include: National meetings twice a year; coordination of a social network site to disseminate information about deafblindness; annual deafblind awareness training sessions for service providers, family members and carers in rural Australia, and training to be provided in e-communication technology for two people with deafblindness living in rural Australia each year.

Meredith Prain

Able Australia

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## **Canada**

DeafBlind Ontario Services

Founded in 1989, DeafBlind Ontario Services is the largest not-for-profit organization providing residential and community services to adults who are congenitally deafblind across the province of Ontario, Canada. Our service model ensures our over 50 clients' goals meet their desires, preferences and abilities through a person-centered approach delivered by specially trained Intervenors. Our Community Services programs include REACH, SEA and Tremplin. Our REACH program provides specialized expertise and support for adults who are deafblind or individuals with a sensory loss and various communication needs living in their family home, nursing homes, foster homes, group homes, special care facilities, etc.

The Sensory Exploration Arts (SEA) Program was created to promote and foster artistic and creative expression among individuals with sensory impairments. Participants include clients of DeafBlind Ontario Services as well as other community agencies supporting individuals with physical or sensory impairments. The inspiration for this program came from SENSE Scotland's Arts and Wellbeing program.

DeafBlind Ontario Services opened a new chapter in our service delivery model last year, launching a new program under our Community Services umbrella called Tremplin. Tremplin is the French word for "springboard" or "stepping stones". This new model of service delivery is offered to individuals who are deafblind in the Ottawa area whose first language is French. We are pleased to offer this specialized community program, the first of its kind, for four individuals who are deafblind.

Tremplin is a blend of our current residential and community REACH programs. This program is ideal for individuals whose families prefer that their loved ones retain the stability of remaining at home, while being able to thrive in a community program during the day, further allowing them to exercise their independence.

DeafBlind Ontario Services secured a home in the town of Embrun just outside of Ottawa that serves as a base for the Tremplin program. When the clients and their families are ready for full residential living, this home will be ready to accept them 24/7. Two of the four clients of Tremplin have recently moved into this home, with the other two accessing the program during the day.

The Tremplin Program is just one example of how DeafBlind Ontario Services has been able to design services to meet the diverse needs of people who are deafblind, rather than the services defining their needs.

Our challenges with the Tremplin program has largely been around language, as those who are Francophone in Ontario use a different sign language to communicate called LSQ (Langue des signes québécoise). To respect the culture of our clients and their families, we needed to hire Intervenors who were fully bilingual. Many of the Intervenors we hire are trained in house with our TOUCH TM program. TOUCH TM is a specialized training program designed to strengthen the competency level of our Intervenors, part of which includes Total Communication methods and understanding the role of the Intervenor. Since most LSQ instructors live in the adjacent primarily French speaking province of Quebec, it was a

challenge to find someone who could train our new Intervenors on the communication methods of LSQ.

The province of Ontario will also be adopting a French Language Services Act in 2014, whereby agencies who provide service in French designated areas (Ottawa being one of them), must do so in both English and French. Most of our funding comes from the provincial government, however, none of that funding includes dollars for translation of organization materials, website, etc. We have created a plan on how we can address these challenges going forward, and have implemented them as part of our strategic plan.

Developing new community partnerships in the Ottawa area will be paramount to our success in delivering services to a Francophone community. We look forward to the journey we embark on transitioning two of our Tremplin clients to full residential services, and strengthening the community aspect of the clients who access this program by day.

Susan Monahan

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## **Guatemala**

### **Friends of FUNDAL and FUNDAL:**

#### **An American Non-profit Group Supports the Work of FUNDAL, a School for Deafblind Students in Guatemala**

It wasn't until I stepped off the plane and onto the campus of FUNDAL's new school building for deafblind students did I fully realize the importance of the planning the Friends of FUNDAL group had been doing hundreds of miles away.

I came to Friends of FUNDAL with no knowledge of deafblind issues, but I had traveled to the beautiful country of Guatemala several times before and had been impressed with the wonder of the "land of eternal spring" and the inherent kindness of its people.

I had, though, been an English teacher for thirty years and knew those "aha moments" when students understood a concept for the first time, as deafblind children must, when they realize touches on the hand are a way to communicate. I knew the satisfaction that came as a student's literacy skills improved steadily. I knew what it was like to work in a supportive environment with dedicated professionals who cared deeply about their students and celebrated the progress of each child. I loved being part of a creative community dedicated to education. That's

exactly what I found at FUNDAL, Guatemala's only school dedicated to teaching deafblind students.

FUNDAL, a nonprofit NGO, opened its doors in 1997 and provides educational opportunities to students primarily with deafblindness who often also have multiple disabilities. FUNDAL, (Fundación Guatemalteca para Niños con Sordoceguera, Alex) serves approximately 50 students at one of its three campuses in Guatemala (Mixco, outside of Guatemala City, Quetzaltenango, and Huehuetenango both in the western part of the country). FUNDAL also works closely with the families of its students so that parents or siblings can help learning continue when students return home. In fact, FUNDAL's outreach and home visitation programs are not only critical to helping students continue to learn but also help FUNDAL develop a sense of community with the families of the students it serves. Most impressive are FUNDAL's stated values that seek to treat everyone with respect and dignity, to coordinate the efforts of family members and professional educators to help students, but first and foremost to offer love, the primary value that inspires the wonderful work of the school.

In the spring of 2012, my family and I toured the new facility of FUNDAL at Mixco, Guatemala with Diana Bonilla Sinibaldi, daughter of FUNDAL's founders, who made the space, which was to open in the next month, alive with possibilities. As we talked, the large open space still under construction seemed perfect for group meetings with the families that came for services, often from a long distance away. The individual rooms to the side made small group interaction possible. Along with the large windows in the rooms, the sky light in the center of the building filled the space with natural light. My children, ages nine and ten, giggled at the dog and the chicken they saw out the window while I marveled at the engineering miracle and construction magic that had turned a piece of useless steep land into usable space, several floors high, for learning and family support.

At one point on the tour, Diana introduced us to her parents, Helen and José Bonilla, whose love for a small deafblind child had grown into a vision for a school for deafblind children and now was the largest school of its kind in Central America. The Bonilla family welcomed me and my family most sincerely to the school, their warm words of connection quite sincere. "You are part of this work," they told us. It was at that point, I think, that the school became more than a building with fresh paint and covered ramps for wheelchairs going between floors. The school became an extension of the family's dream for their son Alex and a dream that we in Raleigh at Friends of FUNDAL (FOF) could be a part of as well.

Friends of FUNDAL was the vision of Grace Bullen, a parent of two children adopted from Guatemala, who has worked with deafblind people as a volunteer, as a certified sign language interpreter (CSC) and as a Certified Orientation and Mobility Specialist. Grace volunteered at FUNDAL in 2007, and came back inspired to start Friends of FUNDAL. With other adoptive parents and interested professionals, Friends of FUNDAL (FOF) was founded a few years later and is now a 501(c)(3) nonprofit based in Raleigh, North Carolina. FOF supports the work of the school through programs such as early information for deafblind children and vocational training for older students.

Grace's vision and now the vision of the growing network of FOF board members, donors and contacts is to help children with deafblindness and/or multiple disabilities and their families by raising awareness and providing financial support in the form of grants to FUNDAL for everything from construction materials to teacher training. Friends of FUNDAL's mission also is to develop resources and support services and programs for other Guatemalan organizations that work with deafblind children, adolescents and their families.

The relationship between the American non-profit and the Guatemalan school continues to grow as Diana Bonilla Sinibaldi de Soto has traveled to the US and specifically to the North Carolina Triangle area several times in the past year. While in NC, Diana shared the story of her family's journey with Spanish students at St. Mary's School and International Baccalaureate students at Broughton High School. She chatted with interested individuals over coffee, met with corporate representatives from SAS (business software company) and Verizon Communications, spoke to the NC Hispanic Chamber of Commerce's "Business After Hours" group and shared the work of FUNDAL on La Mega Radio Station so that hundreds throughout the region heard about the work of the school.

The relationship that has developed between these two organizations is complemented by the friendships that have developed between members of the Bonilla family and the families in Raleigh and beyond. My children and I now talk about volunteering at FUNDAL one day and I wouldn't be surprised if both of them continued in some sort of profession that works with deafblindness when they get older.

Donations to Friends of FUNDAL are tax deductible in the United States and FOF is grateful for all donations, and uses them to further the message and mission of education and training of deafblind and disabled youth through grants to expand and strengthen the programs that serve them. If you would like to support the work of FUNDAL or if you'd like to find out more about the school or Friends of FUNDAL, please take a look at our web pages:

[www.fundal.org.gt](http://www.fundal.org.gt)

[www.friendsoffundal.org](http://www.friendsoffundal.org)

We welcome your interest and support and we'd love to have you as part of our extended family.

Wynn Cherry

Raleigh, North Carolina USA

Member of the Board, Friends of FUNDAL

## **Ireland**

### **Deafblind Ireland Ges Roulstone reports:**

Trustees of Deafblind Ireland held their latest business meeting and AGM on 22 September (2012) in Longford. The group were able to reflect a very successful

year, with their 3rd Annual conference on Deafblindness having taken place at the National University of Ireland campus at Maynooth, County of Kildare, on 25 February. The conference was proud to host the first international engagement of Gill Morbey as Dbl President. As keynote speaker Gill spoke eloquently on the conference theme of “Building Bridges”, from her perspective as both a parent of a Deafblind son and CEO of Sense UK, a large provider of services to Deafblind people and their families.

The conference also launched the first course of study in Deafblindness in Ireland for professionals working in our field. The course has attracted 27 participants in its first year and has been a great success. Certificates of completion of the course will be presented to those who completed all 5 modules at the next annual conference of Deafblind Ireland planned for February 2013. The charity has also appointed Kathleen Deasy PhD as its first Development Officer. Kathleen’s role will be not only to run the course and annual conference but to assist with the expansion of services, starting with our first Family Day, currently being organised for April 2013.

Ges Roulstone  
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## Japan

### **“We are all eyes and ears for you!”**

The Deafblind Service Center “SMILE” was established in 1999 by people with deafblindness in Osaka, Japan. Organizers at SMILE have developed various services so that people with deafblindness can lead active lives and be accepted as equal members of Japanese society.

Like in most countries, people with deafblindness are facing countless challenges every minute of the day. Among their many issues in Japan, their social health is of paramount concern. Many of these individuals experience isolation and a great deal of misunderstanding from the people around them. To compound their difficulties, access to resources and services are very limited. There are few options for leisure and recreation opportunities. This has led to increased levels of stress among these individuals, creating damage to their health and general well being. In some extreme cases this has led to their loss of life.



For the leadership in the field of deafblindness in Japan, this has also led to much overwork and serious stress within this group as well as we try to advocate for these individuals.

'Smile' took the first step to deal with this situation by applying for, and receiving, a subsidy from Pfizer Inc., the world's largest research-based pharmaceutical company. With this project four main goals were established: 1) Research on health issues and stress among people with deafblindness; 2) Peer counseling; 3) Study analysis and 4) Networking.

Through this research we are trying to develop a greater awareness of the stress that these people are experiencing. One of the activities of this project is providing peer-to-peer counseling. Through this counseling, we have built a relationship of trust with the deafblind participants. This success has led us to organize more leadership training and networking to improve the individuals' understanding of their own disability and a better awareness of the disability by the people living with and around them.

This project involved 48 deafblind individuals who answered the research questionnaire, which represents about one quarter of the identified people (200) with deafblindness in Japan. This is a considerably large sample of this group, while recognizing that there are likely many more individuals with deafblindness living in Japan.

Our 48 deafblind participants (24 males and 24 females) range in ages from their 20's through their 70's. Their communication methods include Braille (5 persons), sign language (25 persons), note taking (1 person) and voice (17 persons), which is considered typical of the communication abilities of deafblind people in Japan. Our counseling interviews require about 2-3 hours to portrait as much of their personal life history as possible

Some major findings from these interviews

- Many deafblind individuals have given up leisure activities and hobbies due to their loss of sight and hearing.
- There exists a large gap between those who have good quality of life and those who don't.
- There are many deafblind people who cannot communicate with their own family members. Their only communication might be limited to "supper ready", "time for bath", etc.
- Some individuals studied to be qualified as practitioners of massage therapy, acupuncture and moxibustion (traditional Chinese Medicine therapy). However they are now not able to use this qualification because few employment positions are available to them. If employed, they have difficulty in communicating with clients and co-workers; resulting in them giving up their profession.
- Most of them are disappointed with their situation and they feel there is no other way to live but in an institution, when their sight or hearing totally deteriorates. A respondent told us that "when she loses her residual hearing she was going to divorce her husband, leave her family and move to an institution".

While these findings were concerning to us; it offered us a big challenge towards learning what can be done to help these individuals improve their quality of life and maintain their independence.

We are continuing to deal with these problems in several ways, networking and leadership training.

### Networking

Deafblind people have told us about their difficulty in having hobbies and participating in leisure and recreation activities. Through networking we were able to brainstorm ideas with them to help these individuals have hobbies, and enjoy their leisure time. We intend to continue this networking with others outside our organization to exchange experience and practices.

### Leadership Training

When the individuals become deafblind they tend to become more passive and want to give up doing things they did before. It is true that deafblindness is a severe impairment, and these individuals are forced to use more time, energy and finances to carry out their activities. Through this leadership training we are attempting to raise their understanding that they are capable of doing whatever they want. Having said this, we are becoming increasingly aware ourselves, that these individuals can only accomplish this through improving accessibility and creating better understanding about this disability among the rest of society.

It is in this area of better accessibility and public awareness that we need more promotion. To better do this in our country at SMILE, we need to learn from the experience of other countries. We are asking the readers from other countries for your information and recommendations for best practices. We do look forward to your contact. Just email me! Your comments and suggestions will help us to take the next steps in helping these individuals. None of us want to see another life lost because of deafblindness. Let's work together for this challenging issue.

We are very happy to be interviewed by the world's largest magazine "Big Issue" in November 2012 about our project. We hope there will be the day come that people don't just know Helen Keller; but that they know their neighbor with deafblindness who may be living next to them.

Akemi Fujii and Shin Kadokawa

SMILE

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## **Jordan**

## **An Inclusive School for Deafblind Children in Jordan**

By definition, Inclusive Education seemingly excludes special schools. How then can a special school that is characterized by its disabled community affiliate with an educational model that promotes the full participation of students with disabilities alongside non-disabled students?

The Holy Land Institute for the Deaf in Salt, Jordan has pioneered a solution. As its Director says: “Simply change the parameters of ‘the standard – of what is considered normal’. While still using the written community language, why not use the special (Sign) language of Deaf persons for communication. Then require all learners, teachers, and other staff to use that language.”

This school in Jordan includes persons who are Deaf, hearing, hard-of-hearing, Deaf–intellectually or physically challenged, Deaf–cerebral palsy, etc.

The deafblind unit that currently accommodates and educates nine deafblind children was recently expanded to take in six additional children. Deaf students embrace their deafblind peers, interacting with them on both formal and informal bases. The environment seems ideal: the deafblind children are unlikely to fit well anywhere else, given their initially poor or aberrant communication skills, while the Deaf children are uniquely gifted to learn alongside them, given their fluency in visual as well as tactile communication.

By welcoming individuals with co-occurring disabilities (or none, for that matter), the Holy Land Institute has established a path for successful Inclusive Education in Special schools. Such initiatives succeed when a school recognizes its specific strengths and then includes differently-abled children who react positively to those strengths.

In light of the Deaf community’s unique strengths in visual and tactile communication, a successful Inclusive school for the Deaf will maintain a fully committed signing environment. In this context, Sign language will be associated not with a disability, but with a specific culture – as it should be. The school is special not because its students are disabled, but because their language is different from the majority language, much like ‘foreign’ language schools. Any other approach will not sufficiently utilize the students’ natural strengths (both Deaf students and those with co-occurring disabilities) and thus will not be seen to practice Inclusive Education.

As Hamzeh (Deaf) and Mohammed (deafblind) demonstrate, Inclusive Education at the Holy Land Institute for the Deaf is thriving.

William Stell 1

What is the Holy Land Institute for the Deaf?

The Holy Land Institute for the Deaf, under the auspices of the Arab Episcopal Church in Jerusalem and the Middle East, was opened by HM the late King Hussein in 1964.

Vision: HLID aims to enable Hard-of-Hearing, Deaf and Deafblind people to participate meaningfully in family and community and to make their unique and valuable contributions to an inclusive society.

Mission: HLID provides and develops comprehensive, effective and efficient services in Jordan and the Middle East. Among these services are quality education for the

Deaf, knowledge management, teacher training, development of skills and values and the production of educational materials and resources.

The Deafblind unit at HLID which first started in 2001, is the only such facility in the Arab Middle East, providing hope and empowerment to four boys and four girls, ranging in age from four to seventeen years. According to Rehab Haddad, School Principal, "Patience and consistent training are the keys to empowering these young lives. Every day the staff observes a little more progress in each child. One highlight was to see an older Deafblind child helping a younger one. Another was to see several of the Deaf students helping the Deafblind children, and finding that in doing so, they themselves also learn so much. Perhaps we are seeing here a different paradigm of truly Inclusive Education.

For more information, contact:

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William Stell is a recent alumnus of Wheaton College in Wheaton, Illinois. He is currently serving as a volunteer at the Holy Land Institute for the Deaf in Salt, Jordan. In August 2013, he plans to begin pursuing a Master of Divinity degree at Duke Divinity School.

## **Kenya**

### **DbI President travels to Kenya**

As well as attending the ADBN conference in Sweden in November 2012, I am lucky to have been able to combine Sense and Sense International roles with my DbI responsibilities during a visit to Kenya also in November 2012.

Sense International supports a number of programmes across Kenya, Tanzania and Uganda. Geoffrey Atieli, the Director of Sense International East Africa, took me around some partner organisations where I met some wonderful people and saw their work first hand.

On this occasion I was interested in vocational training and visited Kerugoya School for the Deaf which has a Vocational Unit attached to it. Muturi, the head of the deafblind unit, introduced me to the students. It was really interesting to see the

range of skills the deafblind people are learning, including carpentry, weaving, horticultural, animal keeping and a range of arts and crafts. Many thanks to Jaycee Mwangi Deputy Head and Grace Murimi the Headteacher of Kerugoya who went out of her way to meet with me.

I also saw some wonderful integration at Kilimani School which is primarily for mainstream children. The integration and caring between mainstream, visually impaired and deafblind children was indeed impressive. Mr Wasike, the Headteacher, Trustees and staff made me exceptionally welcome. Rose Kaati the head of the deafblind unit introduced me to the children, and her staff team and I saw a range of products the children had made. The children also entertained us with songs and dance.

I visited the Nairobi Family Support Services located in Kibera (a large slum area). Hannah Mwangi, the co-ordinator, and her staff team support 25 deafblind children and their families. Like all the dedicated professionals I met, their work, often undertaken in really difficult circumstances, is inspirational.

As I travelled I was reminded of Joe Morrissey and CBM as they were key to establishing some of these services so many years ago. Joe it was a real privilege to visit the schools, learn how they have grown and see the children flourish.

Gill Morbey, Dbl President

## **Malawians with Vision Impairment and Deafblindness react to the Central Reserve Bank of Malawi about their recently introduced new currency**

According to the Nyansa Times (June 10, 2012), the Reserve Bank of Malawi may be forced to go back to the drawing table to redesign and reprint the newly introduced banknotes as they do not have features sufficient to enable people who are blind to detect and use them.

The Central Bank was insensitive to people who are blind or low vision as it proceeded printing the bank notes without having finalized the consultation with Malawi Union of the Blind/African Federation of the Deafblind. The Union has complained to the Central Bank that it did not consult them fully before introducing the new banknotes which are all of the same size but with different monetary value. Executive director Ezekiel Kumwenda said: "The bank was expected to come back to us before finally introducing the banknotes but they proceeded and as a result the banknotes do not have the features and people who are blind cannot use the banknotes because they cannot differentiate the notes."

One of the required features are dots on the bank notes. Kumwenda said the banknotes have the dots but they are too small. He said his union complained to the Central Bank which promised to look into the matter.

Central Bank spokesperson Ralph Tseka confirmed receiving the complaint and said the bank will look into the matter “soon”.

An Awareness Campaign was launched

Rather than undertake a re-issuance of new currency, the Central Bank reacted to the complaint through funding an awareness campaign which was meant to explain the salient identification features of the new currency series for the concerned citizens.

The awareness campaign was undertaken throughout the country of Malawi from the 29th of July to 14th of August, 2012, through a joint venture involving the Malawi Union of the Blind /African Federation of the Deafblind, the Visual Hearing Impairment Membership Association (VIHEMA) and the Reserve Bank of Malawi (RBM).

The objectives of the awareness campaign were twofold: To sensitize Blind and Deafblind people of Malawi about the banknotes and coins in use and to equip them with skills on how to differentiate between real and fake notes.

The methodology of the campaign included: receiving suggestions for future changes to address the concerns of Deafblind people; explanation of the role of the Central Bank; suggesting techniques to those visually impaired and their assistants for identifying the front/back faces of banknotes and other general recognition features; identification techniques for counterfeit currency and proper handling of banknotes, etc.

The objectives of money identification campaign exercise were achieved as: Deafblind persons became better sensitized to the new banknotes; they acquired skills on how to differentiate between fake and genuine notes; they were given the opportunity to express freely their views and suggestions about the new notes, etc. Observations made by Blind and Deafblind people during the awareness sessions included: Many of the notes of different currency are of similar size; the similar colour of the different banknotes are difficult for them to differentiate; many faces on the banknotes are confusing because they don't know who is pictured on which banknote; the identifying touch features (raised dots and paper thickness) were not discernible enough for them to determine the size of the currency. The only satisfaction they expressed with the new banknotes was that they can now carry large sums of money in a small pocket!

Challenges expressed about the awareness campaign included: Some of the Deafblind persons did not come to the session because there was no transport reimbursement and lunch allowance since many of them had to travel long distances; some roads were impassable and this caused delays in reaching the location of the center; the number of days allocated for the review was not enough in some locations, etc.

Recommendations for future issuance of new currency: Make sure that the sizes of banknotes differ according to currency value (i.e. K1000 note be the largest; K20 note the smallest); colours of different bank note should be different; ensure the touch features are raised and different for each currency value; ensure that Blind and Deafblind people are fully engaged before issuing any new currency.

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## UK

### **A forum for friendship in the UK**

Colin Anderson received a warm welcome when he recently visited the Wigston Forum in Leicestershire.

When members of Sense's Wigston forum come together for their monthly meeting they greet each other warmly as old friends. "How are you feeling Ron?"

"Do you still get that flashing with your sight?" "Don't worry, you'll get used to it."

They look out for each other, share tips and have a laugh about the challenges life brings.

In fact, they have only known each other for a year or so and it has taken time for them to build up confidence and trust. Some found their way to the forum via their local church, others from social services and the local vision resource centre.

"It's surprising how many people with sight and hearing problems are out there," says June Jones who is a member. "That's the beauty of these forums – you pick up all sorts of experience of how people get around things."

Most of the members of the forum have sight and hearing impairments but partners are also welcome too. They also benefit from the support and company and may be better placed sometimes to organise practical arrangements. "This forum is marvellous," says Pat Turnbull whose husband Stan is dual sensory impaired, "it has made our lives worth living."

Today, after a good chat and a cup of tea, June demonstrates an audio CD player she uses to play her RNIB Talking Books. She explains how it works and the others pass it around and try it out. Then, Fred Osbourne treats everyone to his rendition of 'Albert and the Lion' a famous Stanley Holloway monologue to warm applause and laughter.

The group members take charge of many of the activities at the forum and plan what they would like to do in future meetings. For example, one person suggests that they might all go away on holiday together? They all agree that that might be a good idea and no doubt that will be a subject for lively discussion when they meet again in a month's time.

### Better on the buses

The Wigston Forum also raises awareness of deafblindness and recently invited Michael Cartwright, Arriva Buses General Manager along to raise concerns about local bus services. These included that some members had fallen over after buses had pulled away too quickly, buses jerking upon stopping, high onboard

temperatures causing discomfort to guide dogs and members with visual impairments having difficulty knowing when buses would arrive.

There were a number of useful practical outcomes from this:

- A member of the Arriva training team will visit a future meeting so that disability awareness and careful braking can be emphasised in training sessions.
- Mr Cartwright will suggest to councils that deafblind identifiers can be added to bus passes if the passenger would like the bus driver to know that they are dual sensory impaired
- He will talk to the Arriva engineers to ensure that bus heaters are switched off during the Summer
- The forum members will send a letter supporting the introduction of audio announcements and will track any future introduction of audio equipment.

The Forum members were very grateful to Mr Cartwright for coming along. "I think Michael Cartwright's visit to our forum was very constructive," said Lynda Jones: We were able to tell him about our specific needs and problems and gained some useful information."

For more information about friendship forums, contact: Colin Anderson  
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## **Uganda**

### **Mainstreaming Deafblindness in Teacher Education in Uganda**

**by Mr Eria Paul Njuki, MA (lecturer Kyambogo University), Mr Locoro Victor, MA (member academic board Kyambogo) and Ms Nicoline Mostert, MA (Project manager Uganda, Kentalis International)**

#### **Background**

In Uganda, disability issues in general have been accorded a high political profile over the past two decades. The efforts have largely been through affirmative actions enshrined in several important documents including the Constitution of the Republic of Uganda (1995) among others. Unfortunately, the commitment towards disability compared to other developmental issues in terms of implementation remains low (Kandyomunda, Ingdal, Qutteina & Mogen, 2012). Indeed, like in many countries world-wide, the number of Deafblind persons in Uganda is still unknown. Therefore, service development for people who are Deafblind in Uganda has to date rested in the hands of Non-Governmental Organisations (NGOs) spearheaded by Sense International – East Africa.



Over the past few years, Sense International (Uganda) together with its partner organisations has supported local initiatives which include provision of financial and technical expertise at institutional and family levels. Most efforts have been directed towards creation of awareness about Deafblindness, supporting schools with units for children who are Deafblind and supporting community-based activities including families in the care of their children. However there is still a big gap in the availability of professional skills because there is no existing training program in this highly specialised area of disability.

In order to have more professionals and therefore create a more sustainable support system for Deafblind persons in Uganda, Sense International Uganda and Kentalis International in partnership with Kyambogo University started a 3 year project on the development of a professional training program for people working with the Deafblind.

In 2011, a baseline training needs survey was undertaken with the following specific objectives:

- To analyse the needs of people with Deafblindness / Multi Sensory Impairments (MSI) in the communities
- To analyse the capacity, number and needs of professionals specializing in Deafblindness/MSI
- Identify content for a curriculum for a sustainable university program for:
  - Training teachers and
  -

Community Based Rehabilitation (CBR) professionals on Deafblindness/MSI

- Develop a competency profile of a lecturer of the Deafblind or MSI teacher training program.

The findings of the needs survey indicated that:

- There was an urgent need to establish and design a course for teachers and Community Based Rehabilitation (CBR) workers of children with Deafblindness / MSI such that Deafblind children in Uganda can access quality education and related services.
- Training personnel in Uganda should start with a practical certificate course, followed by a diploma course (teacher training)
- The competence profile of a lecturer to lead the teacher training at Kyambogo University in Kampala should include: interaction, (tactile) communication, sign language and braille, orientation and mobility, psychology and neurology, how a person with Deafblindness experiences the world, counseling and guidance within the communities and developing a curriculum.

Progress made to date

Several activities have been implemented since the dissemination of the needs assessment report. They include:

- A Memorandum of Understanding (MoU) was signed between Kyambogo University (Uganda) Sense International (Uganda) and Kentalis International (the Netherlands) in December 2011 with an aim of developing a new program at the

department of Special Needs Studies in the area of Deafblindness. The project period is 3 years (2011 – 2014)

#### Visits and Trainings:

- In October-December 2011: Two lecturers from Kyambogo University were trained in the Netherlands for exchange of expertise and ideas concerning the curriculum.
- In May – August 2012: Professionals from Kentalis International conducted trainings in Kampala in the field of orientation and mobility, communication and interaction, tactile sign language and assessment.
- In September–October, 2012: Two lecturers from Kyambogo university were trained by the multidisciplinary Deafblind team of the Diagnostic Centre of Kentalis International.
- A certificate program has been developed targeting teachers, parents, (CBR) workers and other professional from other service areas. The program will run for two academic semesters but it is currently undergoing the accreditation process by the relevant organs of Kyambogo University.

Several expert meetings are taking place to harmonize the lessons learned from the visits and trainings with Sense International (Uganda), Kyambogo University, Kentalis International and the donor community. The focus of these meetings was to map out both the short and long term activities and the financial and technical resources required prior to the implementation of the proposed training at Kyambogo University. All previous activities have been implemented using funds from Cordaid (the Netherlands) and coordinated by both Kentalis International and Sense International Uganda.

#### Proud and Confident

The three parties are very proud of the results so far and confident that the new training will take off in August 2013. This program will raise a sufficient amount of experts to ensure good quality education and related services for the Deafblind community of Uganda.

### **Musical Perception of a Deafblind Cochlear Implant User**

A new DVD documentary titled 'Musical Perception of a Deafblind Cochlear Implant User' was released in November 2012. It was written and produced by Russ Palmer (music therapist), who had his first Cochlear Implant in 2004 and second CI in 2011. In February 2012 he performed for the first time with a music band consisting of guitars, bass, and drums. This concert was held in Finlandia Hall, Helsinki, Finland. This is a unique challenge for someone who is deafblind (hearing and sight impaired with Usher syndrome), to sing and play with the musical band. This 45 minute

documentary includes interviews with professionals, friends and band members who have co-operated with Russ over the years as well as extracts from the concert. As a child Russ developed his musicality by singing and playing various instruments with his father. His main instruments are guitar and piano. As a songwriter he composes his own music and in 2009 he released his first CD Warm Summer Days, a musical biography.

This educational DVD will appeal to cochlear implant manufacturers, academics, professionals, teachers, parents and cochlear implant users who wish to explore their own musicality.

For more information, contact: Russ Palmer at [rpalmer2@tiscali.co.uk](mailto:rpalmer2@tiscali.co.uk) or [www.russpalmer.com](http://www.russpalmer.com)

The Ear Foundation at [www.earfoundation.org.uk](http://www.earfoundation.org.uk)

For the Warm Summer Days CD: [www.earfoundation.org.uk/shop/items/107](http://www.earfoundation.org.uk/shop/items/107)

## **The Danish Association of the DeafBlind (FDDB) announces:**

### **the English version of their book about Haptic Communication**

The Danish Association of the DeafBlind (FDDB) is proud to present the English version of our book about haptic communication which is used for visual descriptions for deafblind people by drawing signals on the back. Haptic communication is an extra communication system that makes it possible for deafblind people to know how people react and what is going on – right now in the situation.

### **103 Haptic Signals – a Reference Book**

The book is a collection of the most common haptic signals used by deafblind persons and people with visual and hearing impairments in Denmark. The signals have been developed and chosen by deafblind persons in Denmark over several years. The book can be used for training and further development of haptic communication. It is our hope that the use of haptic signals will become a natural element within visual interpretation to all deafblind persons.

FDDB believes all deafblind people in the world deserve to know about haptic communication.

Price: 13 Euros

The book can be purchased by contacting FDDB at email:  
[fddb@fddb.dk](mailto:fddb@fddb.dk)

Free pdf-version

FDDB welcomes individuals and organizations to download a free pdf-file of the book from our webpage: [www.fddb.dk/udgivelser/boger-pjecer-og-kataloger](http://www.fddb.dk/udgivelser/boger-pjecer-og-kataloger)

Here is what Danish deafblind persons say about using haptic signals:

“I will never attend a meeting again, without getting haptic signals on my back.”

“Getting haptic signals makes such a difference – now I know when people smile back at me, and what happens around me.”

“I can now participate socially, when I meet people. Before, I never knew when to speak or when to smile.”

Kirsten Malmbak (Chairman FDDB) and Pia Hesse (Information staff member)  
The Danish Association of the DeafBlind (FDDB)  
Blekinge Boulevard 2, 2630 Taastrup, Denmark  
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## **Network News**

Acquired Deafblindness Network

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Social-Haptic Communication Network

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Tactile Communication Working Group

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Usher Study Group

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## **Outdoor Network**

### **Joe Gibson reports on the First Outdoor Network Activity in the Highlands of Scotland**

During the last week in September, 2012, 34 people including eight deafblind people from Scotland, England, Norway and Denmark and six film crew from Scotland & Norway made their way up to Aviemore in the North East Highlands of Scotland. We were based for the week at Glenmore Lodge, Scotland's National Outdoor Centre.

Monday

At lunchtime today the Sømådalen Norwegians who had arrived the previous evening came for a look around TouchBase, Sense Scotland's head office in Glasgow. I packed my car full of equipment and we all left early in the afternoon heading north. When I arrived at Glenmore Lodge the various Scottish and English participants had already arrived and helped get a large dinner ready. The Sømådalen Norwegians arrived later after a scenic journey from Glasgow, and later on in the evening the Andebu Norwegians arrived having driven from the airport in a torrential downpour. We all ate dinner together and I tried to work out who would be in what rooms before everyone settled for the evening.

## Tuesday

The next morning, after breakfast, the Aalborg Danish arrived and we had a morning briefing where I introduced our instructors and we talked about the days activities. Today was a journey from up in the mountains back to the centre. We all got dropped off at the "Sugar Bowl" car park and set off in the heavy rain with Nick one of our instructors for the day. The path we followed had some steep rocky sections, which everyone managed ok and despite the rain everyone seemed happy. Slowly we got lower down the mountain and ended up in a forest by a river. We all stopped and regrouped where the river fed into Loch Morlich and had our lunch. After lunch some people chose to cross "through" the river using a rope as a guide while some walked back through the woods to a bridge. On the other side of the river there were some canoes waiting for us to paddle across Loch Morlich to the watersports centre and from here we made our way back to Glenmore Lodge. Everyone then had a chance to get changed and warm up before dinner. For dinner we all made "Dagfin Bowls"; everyone cut up chicken and whatever vegetables they wanted and put them in a foil dish. These were then placed in the oven; we would normally do this over the fire but as it was still raining outside we cooked in our lodges. After dinner people had the opportunity to use the swimming pool in the centre and try out the climbing harnesses we would be using tomorrow.

## Wednesday

This morning after our briefing we set off from the lodge walking up into the hills on the Glenmore Forrest side. It was still raining but not as cold as yesterday. We walked for a couple of kilometres until the big wide path stopped. Again we regrouped and all had our lunch; then unbelievably the rain stopped and the sun came out! After lunch we followed a narrow path that had some very challenging sections. Progress was slow but eventually everyone got to the section where a small rope slide had been set up. At the end of the narrow path was the beautiful "Green Lochan" and from here it was an easy path back to the lodge (or for some people a ride in the back of the mountain rescue Landover! Once everyone had a chance to change and get dried the Danes went off to set up the fire place near the river at the back of the Lodge while everyone else helped me set up the two Lavu's (tepee tents). Once the tents were up we all made our way down to the fire place and had a Danish meal of meat and potatoes sitting around a huge fire next to the river. After dinner some people went up to the bar and some slept in the lavu's.

Thursday

Today everyone had a free choice and everyone decided to go to the top of Cairngorm Mountain on the funicular railway. This was a chance to see the whole of the Cairngorm National Park from near the top of one of Scotland's highest mountains and buy souvenirs. In the evening we had a Scottish meal of Haggis, mashed potatoes, stovies and black pudding. Murray from Scotland entertained everyone playing his accordion and reciting some Scottish poetry – there was even some dancing! The Danes had to leave late on the Thursday evening and everyone else left the next morning after a busy, wet, fantastic week.

This was the first Dbl outdoor network event and was a great success with lots of shared experiences to remember and talk about. It also generated lots of discussion about the outdoors activities and the nature of the network. Thank you to all those involved for a great week!

Joe Gibson, Sense Scotland  
Dbl Outdoor Network  
Email: [jgibson@sensescotland.org.uk](mailto:jgibson@sensescotland.org.uk)

## **ADBN Network**

### **Liz Duncan reports:**

As I write this, I am thinking back to our very recent Conference in Lund, Sweden at the beginning of November. It was a happy, successful event with delegates from all over the world coming together to share their experiences, knowledge and questions about Acquired Deafblindness.

We had the largest number of workshops that we have ever been able to offer (36 in total) and speakers or presenters from just about every continent. The speakers covered a diverse range of topics ranging from Technology and what a difference it can make to daily life, through to personal experiences of being both a Deafblind person and a professional in the field of Deafblindness. It was such an exciting event to be part of, made even more so because many delegates had never attended an International Conference before, so there was a real 'buzz' to it all. On behalf of the ADBN coordinating group, I would like to formally acknowledge and thank all the speakers and presenters for their contributions to the Conference.

The local planning team in Sweden did a fantastic job of putting the conference together and I hope that they are still, a month later, feeling very proud of themselves. And I hope that life has returned to normal for them!

Many people were surprised by how much had been crammed into 2.5 days – and were even more surprised by how tiring it all was, but the opportunities for all of us to come together and learn and share with each other are so precious that we have to make the most of it.

Of course, it's always a challenge for the Coordinating group to know exactly what should be on the programme – and what should be left out, but we do use the feedback and comments that we get both during and after the Conference to help us make those decisions and plan the next event, so if you were a delegate and haven't told us what you thought of it all, please do so!

It was great to be able to talk to so many people during the Conference and also to hear from people when I got back home. So many people came back with new ideas or new areas of interest and new connections with each other – just what we were hoping to achieve, but so great to know that it's really happening.

And if you would like to know more about the Conference, or see some of the photos, then please visit [www.skane.se/adb2012](http://www.skane.se/adb2012).

Now that the Acquired Deafblindness Network is growing and reaching out across the world, we have to find different ways of helping people to connect with each other outside of the conference years, so if you are reading this and have some ideas, or if you want to be a part of the Network, but can't attend the conferences, then please make contact with us. We are actively working on ways and ideas to help establish connections for people and need to know what people think or want. And now, the Coordinating group is beginning to think about the next Conference in 2014. Sense is the host and it will be held in Belfast, Northern Ireland. Belfast is a very beautiful city, definitely worth visiting, so we hope that you will come for the Conference and stay on for awhile to explore.

Best wishes

Liz Duncan

Email: [Liz.Duncan@sense.org.uk](mailto:Liz.Duncan@sense.org.uk)

## **Tactile Communication Network**

### **Bernadette Van Den Tillaart reports:**

In 2001, persons from Europe and the United States established the Tactile Communication Group under auspices of Deafblind International (DbI). This group focused on developing insights and practical suggestions regarding tactile communication with congenitally deafblind people.

The initial members, Bernadette Van Den Tillaart, Barbara Miles, Gunnar Vege and Barbara Bettenmann, were able to meet through initial funding from former Viataal (now Kentalis) and Zentrum Tanne and continued funding from Perkins International and Andebu Dovblinde Senter. When Barbara Bettenmann's daily work in Switzerland prevented her from further participation, Paul Hart joined the group and Sense Scotland became a funding organization as well. We are very grateful for the contributions of these organizations and the continued support of Deafblind International.

Over the years, the discussions and the focus of video examples shared by the members of the group moved from just thinking about techniques and curricular or



developmental steps to fundamental thoughts about what it might mean to be congenitally deafblind and live in a rich tactile world. The responses of participants in our presentations in Dbl conferences supported our thinking and direction. To share these ideas with a wider community, we started working on a movie.

### Landscape of Touch

'Landscape of Touch' follows the experience of people – both deafblind and seeing/hearing, as they explore, interact and communicate with each other in the tactile world. When we write about deafblind people, we are referring to both children and adults.

A person with sight and hearing needs a radical shift in perspective in order to experience and understand the world from a tactile perspective, which is the way that congenitally deafblind people experience their world. When tactile experiences become meaningful for both partners in an interaction, this becomes the foundation for exploration of new environments, development of meaningful communication, and the building of friendships.

This DVD offers specific images that show this shift in perspective that is required to enter the rich unique world of tactile experience that is inhabited by congenitally deafblind people.

The title of the DVD, Landscape of Touch, refers to a shift from distant landscapes, often associated with living in a visual world to landscapes that are literally within touching distance – experienced through the sense of touch.

In order not to be distracted from a focus on hands, feet and bodies as they interact through touch with the world around them, we decided to leave out spoken words or terminology. For those who would like to learn more, we will post additional and related materials on the Dbl webpage.

### Universal access

Not using spoken words makes it also possible for people from different cultures or languages to have access to this movie. When the movie was finished in 2010, we started developing a companion guide and making all the final technical arrangements for publication with great support of Sense Scotland and Perkins International. Access for blind persons and deafblind persons was made possible by providing an audio description on the DVD, and by providing the movie, the text of the audio description and a signed description on the Dbl webpage.

### The companion guide

Moving into unknown territory, such as in tactile landscapes, might create unease and misinterpretations. To support viewers of the movie to make a comfortable and open shift towards this tactile experience, in group training or in everyday life with people who are deafblind, we have developed suggestions for viewing the movie; developing reflections and discussions; simulations, and ideas for practice. We strongly suggest that leaders of groups or individual viewers read this section on suggestions as a preparation for their viewing.

It is hoped that the DVD will lead to enhanced shared understanding between seeing/hearing people and deafblind people, and to increased joyfulness in our mutual exploration of the tactile world in which we all live.

Bernadette Van Den Tillaart  
Email:fgenugte-tillaart@telfort.nl

## **Social-Haptic Communication Network**

### **Riitta Lahtinen and Russ Palmer report:**

This message is meant to clarify the aims and objectives of this new Dbl network that was accepted by Dbl in July 2012. Currently this network consists of professionals, deafblind and family members who wish to share their experiences in using social-haptic communication methods and techniques. Social-haptic communication includes haptices (touch messages), which are made of haptemes or grammar elements. Touch messages are applied between two or more people (person to person) in a social context.

### **Aims and Objectives of the Network**

- To establish an international network for the interchange of ideas and experiences.
- Provide training and distribution of information improving services for visually and/or hearing impaired and deafblind people.
- Organising meetings, workshops and seminars
- Writing joint articles from different countries
- Expanding research on social-haptic communication

### **Activities**

International symposia and seminars have been organised in co-operation with different institutions. The first conference "Touch You, Touch Me" was organised in Helsinki 2010. The first Finnish 3-study point national course on social-haptic communication for professionals, including interpreters, has now been established in cooperation with the network.

Basic level social-haptic communication has been also established in the UK with the Ear Foundation (Cochlear Implant organisation for families and professionals) in Nottingham and with the Royal Association for the Deaf (RAD) near London.

### **Forthcoming events:**

Accessibility and Multimodality in Communication Symposium, Turku, Finland, May 30-31, 2013. [tucs.fi/conferences/acmuc2013/](http://tucs.fi/conferences/acmuc2013/)

### **Published articles:**

Lahtinen, R., Palmer, R. & Ojala, S. (2012). Visual Art Experiences through Touch using Haptics. *Procedia – Social and Behavioral Sciences* 45, 268-276.

[www.sciencedirect.com/science/journal/18770428/45](http://www.sciencedirect.com/science/journal/18770428/45)

Palmer, R., Lahtinen, R. & Ojala, S. (2012). Musical Experiences and Sharing Musical haptics. *Procedia – Social and Behavioral Sciences* 45, 351-358.

[www.sciencedirect.com/science/journal/18770428/45](http://www.sciencedirect.com/science/journal/18770428/45)

For further information on previous Touch You, Touch Me seminar in Helsinki, Finland, 2010: [www.pcnet.org/index.php?page=pressevents&type=0&itemid=9](http://www.pcnet.org/index.php?page=pressevents&type=0&itemid=9)

For further information on social quick messages:

[www.kuurosokeat.fi/social\\_quick\\_messages/](http://www.kuurosokeat.fi/social_quick_messages/)

Dr Riitta Lahtinen,

communication researcher

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Russ Palmer, music therapist.

Email: [rpalmer2@tiscali.co.uk](mailto:rpalmer2@tiscali.co.uk)

Web: [www.russpalmer.com](http://www.russpalmer.com)

## **Deafblind International (Dbi) preconference on**

### **CHARGE Syndrome**

**August 24 2013**

**Lille France**

#### Announcement

The preconference from the Dbi CHARGE Network ([www.dbicharge.org](http://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).

Time: 08:30 till 17:00.

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

**SOCIAL-EMOTIONAL SKILLS**

**COMMUNICATION**

#### Expression of interest

If you are interested in attending or have further questions, please feel free to contact:

[Andrea-Wanka@dbicharge.org](mailto:Andrea-Wanka@dbicharge.org).

Or [gail.deuce@sense.org.uk](mailto:gail.deuce@sense.org.uk)

Or [Martha.Majors@perkins.org](mailto:Martha.Majors@perkins.org)

JOIN US!

## **Siblings Network**

### **Sabine Kersten reports:**

Due to some good and sad events since the beginning of this year it again became clear to me that the bond between siblings can mean so much. Brothers and sisters – they learn from each other, they laugh together, they fight and argue and learn to make up again. And they comfort each other when one is sad or in pain. They share secrets and experiences.

But how different can all this be when one sibling has a disability? When communication is not that easy between them, when it is not that easy to play with each other?

How do you bond when your older brother is only at home two weekends a month? Depending on their age, the sibling may feel jealous and left out as most of the parental attention will go to his older brother. They may react upset or even angry, not knowing how to deal with this different situation.

How do you bond when your sister has tantrums and hurts you when she cannot express herself? How do you bond with your sister if you feel ashamed for her?

How do you bond with your brother or sister if you are scared of the consequences of their disability; when you have no idea what will happen to them; when you are concerned for the future?

Siblings may have so many questions that need to be answered. Siblings may feel troubled by all the concerns they may have. The answer to many of these questions and concerns will be information. Just as parents, siblings have a lifelong need for information.

The Dbl European conference is scheduled for August 2013. The Siblings Network will try to be present during this conference to share information and experiences. I hope to see you there!

Sabine Kerstin  
siblingsnetwork@gmx.net

## **Communication Network**

### **Ton Visser reports:**

The group met each other in Groningen, Netherlands, September 27, 2012. The items we discussed were further updates to issues raised in our last report: continuing discussion about the University of Groningen Masters program, plans for

the Open Access Journal, further knowledge development and our new book "Learning from Persons with Congenital Deafblindness".

Most of our meeting we spent on the further development of the open access journal. We plan to have the first edition available around the time of the Lille France Conference, late August 2013.

We made an agenda for our first two meetings regarding the book preparation; one in December 2012 and the second in March 2013. During our initial meeting we plan to start writing the follow up to the initial 4 booklets (previously published) with the help of videos illustrating the concepts; then continuing the process at the follow up March meeting. I expect we will have more news about the entire process in our next report.

Ton Visser

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## **Developing and Testing of a Standardized Assessment System**

### **for Individuals who are Deafblind in Ontario**

Since 2004, Dr. Dawn Guthrie (Wilfrid Laurier University, Waterloo, Ontario, Canada) and other researchers from the University of Waterloo (Waterloo, Ontario) have been working on several projects related to assessment and service planning for individuals who are deafblind in Ontario. These three projects are described below.

#### **Project 1: Developing an Assessment System for Deafblind Individuals in Ontario (2004-2006)**

In Ontario, the Ministry of Community and Social Services (MCSS) funds intervenor services for individuals who are deafblind. There was ongoing concern regarding equity of service provision across the group of deafblind consumers. To address this concern, MCSS funded a research project to develop a standardized assessment tool for this population. This project brought together a diverse group of individuals from the MCSS, provider agencies and a team of researchers and experts with experience in creating assessment instruments for individuals with disabilities. This tool would serve primarily to identify the health and service needs of deafblind clients and would allow for a determination of resource intensity in order to assist with the development of an equitable funding system.

The Deafblind Supplement[1] was created as a new module to the interRAI Community Health Assessment (interRAI CHA).[2] The interRAI CHA was developed by interRAI ([www.interrai.org](http://www.interrai.org)), a multinational not-for-profit research team comprised of researchers and clinicians from over 20 countries. The interRAI CHA is

a modular instrument based on a common core assessment that can be supplemented by additional material to deal with the strengths, preferences, and needs of specialized subpopulations. The Deafblind Supplement was created through several rounds of discussion and feedback with interested stakeholders including MCSS representatives, service providers and deafblind consumers. Pilot testing was completed with 182 clients who were already receiving services through MCSS. The results of this pilot study, including analysis to compare the congenital and acquired population, have been published recently.[3,4]

#### Project 2: Testing of a Standardized Instrument for Assessing Deafblind Individuals in Ontario (2007-2008)

The main goal of this project was to assess the inter-rater reliability of the interRAI CHA/ Deafblind Supplement in a sample of deafblind consumers in Ontario, Canada. A total of 11 assessors, all with several years of assessment experience in working with the deafblind, were involved in the project. Forty-four clients were assessed twice, by two different assessors, to measure the inter-rater reliability of the items. A total of 28 of these clients were congenitally deafblind, and 16, had acquired deafblindness. The kappa statistic was used to assess inter-rater reliability. Overall, the reliability of the assessment instrument was very good with a mean kappa score of 0.59 (sd=0.28). The reliability was in keeping with many other interRAI instruments (e.g., those used in home care and long-term care). Given that MCSS is moving forward with a phased implementation of this instrument, these results provide further evidence of its utility as a standardized assessment for deafblind individuals.

#### Project 3: Incorporating Elements of a Functional Assessment into the Existing Standardized Assessment for Deafblind Clients in Ontario (2009-2010)

The existing standardized assessment (the interRAI CHA/Deafblind Supplement) was originally developed for clients who had already been assessed as being functionally deafblind. Service providers, and other stakeholders, identified a need to include additional information in the assessment to help to determine how a person was functionally using their existing vision and hearing. The goal of the current project is to add additional data elements to assist professionals in identifying individuals who are functionally deafblind in order to match their needs with the appropriate supports in the community. As part of this study, a number of new Clinical Assessment Protocols (CAPs) are being developed for use with individuals with dual sensory loss. The CAPs are triggered based on responses in the assessment instrument. They highlight areas of concern for a given client. The CAPs themselves are created by experts in the field and are written guidelines that include suggestions for further assessment, referrals and/or service planning. They are designed to inform service provider about the most appropriate “next steps” in providing services to each client.

In the fall of 2009, pilot testing will take place using the interRAI CHA/Deafblind Supplement and three new CAPs related to: Dual Sensory Loss, Orientation and Mobility and Communication. The pilot test will also include interviews with both

clients and assessors to understand how the assessment is working, where challenges have been identified and what changes are needed to the existing assessment system.

For further information please contact:

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## **History of Social-Haptic Communication**

**Russ Palmer, Music Therapist & Riitta Lahtinen, PhD, Communication researcher**

Historically social-haptic communication originated when the authors first met during 1991 during the 10th Dbl World Conference in Örebro Sweden. The first social-haptic communication article was published in Proceedings of the 3rd IAEDB (Dbl)

European Conference in Potsdam, 1993 (Palmer & Lahtinen, 1994). This haptic research gave people with acquired deafblindness the framework to develop the methods of holistic and interactive communication further, which later became identified as “social-haptic communication”. The whole process has taken 20 years to develop. Touch and haptics can be divided into two subgroups, social-haptic communication and haptic communication, which should not be confused with each other even though they sound similar. They both have different meanings and definitions.

The definition of social-haptic communication can be found in Lahtinen’s (2008) doctoral thesis and Lahtinen, Lahtinen and Palmer, 2010. Social-haptic communication includes haptices (touch messages), which are made of haptemes, also known as grammar elements. By definition social-haptic communication refers to touch messages between two or more people in a social context (person-to-person). Social-haptic communication methods are usually combined with linguistic information. This gives a greater in-depth quality of information to the deafblind user; while at the same time providing short cut methods and real time information flow. Haptic communication by definition refers to information received from technical devices or objects using active touch. Examples of these devices include computer joysticks, mobile phones or other touch-related devices (See picture 1) which were demonstrated at international haptic research conferences (Lahtinen & Palmer, 2000; [www.eurohaptic2012](http://www.eurohaptic2012)). Other examples of haptic communication, which is sometimes referred as haptic exploration, includes objects being felt or explored through the hands or feet. Examples of the objects that can be felt include raised letters, scale models and touch replicas (Hutchinson, 2012).

## Historical development of social-haptic communication

### 1. Yes & No Haptices

Initially the first haptices identified were the yes and no messages, arriving and leaving a personal space. These initial ideas were published in Dbl’s (previously IAEDB) Deafblind Education (Palmer & Lahtinen, 1994). More thorough analyses on these early developmental stages were made for Lahtinen’s licentiate thesis (2003). Some elements were also published in Dbl Review (Palmer & Lahtinen, 2005) and presented at the 6th Dbl European Conference in Slovakia in 2005. Various courses on using these methods were given to Sense Scotland staff in 1993 and later in 1990’s in Denmark, Norway and Finland. The first academic publication was produced with Manchester University for a special education module (Lahtinen & Palmer, 2000). The development continued over the years and at each step of the way new elements were added to the system. Lahtinen was also collecting data through interviews, diaries and courses during her travels in Europe.

### 2. Social Quick Messages

Social quick messages are elements which are included in the social interaction between two or more people. The social quick message system includes the first identified elements and other interactive touch messages used in social contexts,



such as coffee and tea breaks and with body language reactions from other people in the environment, such as laughing or crying. Let it be noted that the system of using bodyname was introduced at the same time to allow a deafblind person to identify the person coming into their personal space. This material has been translated into other European languages including Russian. (Lahtinen, 2007a & Lahtinen, 2007b; [www.kuurosokeat.fi](http://www.kuurosokeat.fi))

### 3. Emotional Response Hand (ERH)

The body language elements were later collated together and the Emotional Response Hand (ERH) (picture 3) system was introduced at conferences in 1996 (Lahtinen & Palmer, 1996 and 1997). The main purpose of ERH is to allow the deafblind person to identify the nonverbal visual elements of people around them, i.e. body language. These can be adapted if a deafblind person uses sign language, hands-on signing or fingerspelling and spoken language. The ERH can be used either on the back of the hand in terms of a person's face (Lahtinen, 2008; Lahtinen, Lahtinen & Palmer, 2010), on the shoulder, on the person's back or on the side of the leg when sitting side-by-side. This allows a deafblind person's interpreter to use the system flexibly in various situations.

Emotional Response Hand (ERH), Lahtinen 2008

### 4. Environmental Description and Body Mapping

Environmental description allows the deafblind person to gain information on the environment around him or her. For example if one is in a café with an interpreter/guide, the other person can explain the movements of people and what is happening around them when drinking coffee. This is produced through description methods either through the hands or the body. These methods include mapping on the body, e.g. drawing out the positions of tables, chairs and obstacles so that the deafblind person can build a mental picture of their surroundings. This can be supported by describing further details if needed, for example if a table has an unusual shape or if objects need to be described from a safety viewpoint. This may also include showing directions onto the body so that the deafblind person can identify the location of an object or person more precisely. There are also specialised body mapping techniques for applying in specialised settings, such as sport activities (ten-pin bowling), exhibitions, shows or using the computer (mouse location) (Lahtinen, 2008).

### 5. Haptices and Haptemes

Definitions of haptices and haptemes refer to the combination of applying touch messages, words and grammar elements. Haptemes are the grammar elements of touch, such as pressure (light, heavy), speed (fast, slow), location (such as back of hand, back or shoulder), movement (circular, tapping, side-by-side etc.) and hand shape (such as fist or flat hand). Haptemes are like individual letters in a text.

Example letter “y” on its own means nothing, but if one adds “e” and “s” then you have a proper word “yes”. In the same way, your palm as the location means nothing; you have to add the tapping movement of your right index finger to form haptice YES. (Lahtinen, 2008)

Haptices are the individual touch messages like words in the text such as yes, no, angry, tired, happy, in love, tea or coffee. These are different combinations of haptemes. You can express different emotions in haptices by changing the pressure or speed of haptemes. For example, the haptice YES can portrayed as “Oh, yes!” (an excited yes); here there is more pressure and faster speed. Similarly you can change YES to NO by changing the movement hapteme from tapping into a side-to-side movement. ([www.kuurosokeat.fi/en](http://www.kuurosokeat.fi/en)).

By using haptices and haptemes together we can portray messages, emotions, body language and gestures into a more meaningful and spontaneous real-time information.

## 6. Body Story

Body Story originated as a result of Russ Palmer attending a Guided Imagery music therapy course in 1995. At this course the tutor would play a piece of music and tell a story to get the students into a relaxed state of mind – example “It’s a warm summer’s day, you are walking on the beach with sea lapping on the shore ...” The lectures were all in a foreign language and it was not possible to have any translation because it would upset the atmosphere. In order to solve this problem, Riita Lahtinen, who was acting as the interpreter at that time, started to give individual movement elements onto Russ Palmer’s hand and arm as he was lying down.

For example warmth, beach, walking, sea etc., followed along the spoken storyline. As a result, the Body Story (Lahtinen & Palmer, 2005) evolved and was expanded to include many different elements. This allowed the interpreter or professional to create stories, non-verbally, through touch.

## Conclusion

Social-haptic communication approach makes the interaction easier and more efficient among deafblind people, family members and friends, interpreters and other professionals (Lahtinen 1999; [www.fsdb.org](http://www.fsdb.org)). Thus it improves the quality of information for the deafblind person and gives the person more real-time, spontaneous information about the environment around them. Social-haptic communication is now used by acquired and congenitally deafblind people in many countries and has been expanded to other groups such as those who are visually impaired, blind, people with learning disabilities, autistic and medical patients who are terminally ill. This approach is also used by professionals in universities such as phoneticians, who use auditive information in their analyses and cannot concentrate on surrounding sound information at the same time.

In June 2012 the Dbl committee approved the formation of the Dbl Social-Haptic Communication Network, which will allow the professionals and individuals to exchange and share knowledge internationally through the support of Dbl.

Furthermore the authors are now providing 1-6 day courses on social-haptic communication and are collaborating with various organisations throughout Europe.

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## **“Coming to Terms” between Service Delivery and Research**

The field of vision impairment has adopted the terms blind and low vision in order to describe the spectrum of vision loss (Goodrich, Ardit, Rubin, Keeffe, & Legge, 2008; Hellinger & Green, 1955). Similarly, the field of hearing loss uses the terms D/deaf and hard-of-hearing to differentiate severity levels and cultural information (Higgins, 1980). However, in the field of combined vision and hearing loss, terminology has neither been well defined nor adopted internationally. Deafblind and dual sensory impairment are only two of the various terminologies used to describe co-existing vision and hearing loss. Being an emergent area of research, there is an ever-increasing number of players at the table, each with their own perceptions and terminologies, making this an important time to agree on a type of language and terminology when communicating with each other. Stakeholders from policy and management use different definitions of deafblindness than clinicians. Researchers within rehabilitation services use key words and search terms that may not correspond to the choices of their colleagues in fields such as genetics, nursing or medicine. Finally, communication between service providers and researchers (a.k.a.

knowledge transfer or knowledge exchange) can only proceed fluently when we each know what the other means when employing specific terms.

In order to bring some clarity to this situation, our research team decided to investigate the use of terminology among service providers and researchers by conducting a survey, as well as a systematic literature review, analyzing the use of vocabulary in the domain of combined vision and hearing loss. The survey was conducted with the support of Deafblind International, whereby qualitative questions were posted on their web site during the summer of 2011. In addition, we contacted personnel in our rehabilitation network in Montreal, Canada, as well as conference participants at the Premier colloque francophone international sur la surdicécité (First Francophone International Colloquium on Deafblindness), and 139 agencies for the deafblind that were identified through a Google-search. In parallel, we analyzed the utilization of terminologies employed in 809 publications in research journals that made reference to deafblindness.

Our analyses uncovered intriguing differences between the use of the terms deafblind and dual sensory impairment, when comparing clinicians and researchers. Service providers are comfortable using the term deafblind as an all-encompassing umbrella term that describes the entire spectrum of clients, independent of impairment severity, age or order of onset. Researchers, however, striving for more exact communication, preferred the term dual sensory impairment, whereby they viewed deafblind as the extreme of the spectrum, describing the absence of vision and hearing. It is noteworthy that researchers in areas outside of the rehabilitation field generally shied away from the term deafblind. This could be because of their personal perceptions of the terms, or their lack of exposure to communication styles among rehabilitation professionals.

The time seems appropriate to consider terminology, as a point of discussion, to unify our field, and to facilitate communication among the various stakeholders. Following the example of hearing and vision impairment, our team proposes the use of the two most common terminologies: deafblind and dual sensory impairment. In the tradition of rehabilitation service delivery, the large majority of stakeholders seem to use the term deafblind in the context of paediatric sensory impairment as well as in research with clients affected with Usher Syndrome. However, in the tradition of research communications, the term dual sensory impairment has been more commonly used for adult-onset sensory loss and older adults with partial loss, specifically now that they make up the largest proportion of clients in the rehabilitation system for dual sensory impairment (Wittich, Watanabe, & Gagne, 2012). The use of both terms would also allow our clients to have a choice in the language they would like to use themselves when forming their identity. During my own encounters with rehabilitation clients it has always struck us that many older adults with age-related loss reject the idea of being served in a program for the deafblind, since they perceive themselves as neither deaf nor blind. Similar issues have been discussed previously when conducting focus groups with older adults that have both vision and hearing loss (LeJeune, 2010)

Of course, the term dual sensory impairment still contains ambiguity, since it does not specify which two senses are actually impaired. There have been suggestions to

use the term combined vision and hearing loss; however, in publications, we uncovered little use of it. In addition, the question of terminology does not seem equally relevant across languages (Lagati, 1995). However, since the predominant language of publication internationally is currently English, we can all benefit from this clarification of terms. We hope that the topic of terminology will be of interest, and will initiate further discussion. Other parties, such as policy makers, fund raisers and administrator will have their own perspective on the terminology used, given their respective environments. For example, it may be easier to raise funds for a project on deafblindness than for dual sensory impairment, simply because of the inherent associations made by the persons reading and prioritizing the applications. If you have any ideas or suggestions related to this topic, please feel free to contact us at [wwittich@ssss.gouv.qc.ca](mailto:wwittich@ssss.gouv.qc.ca)

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# Kick-Off of EU Project for Deafblind Services in German-speaking Countries

**Press Release, October 11, 2012**

For decades, German-speaking specialists who work with deafblind and dual sensory-impaired people have discussed the idea of forming a network, but have not been able to realize this goal. The tremendous need for such a network (or working group) became very apparent at the recent Deafblind International (DbI) conference in Brazil. In countries such as the United States and the Scandinavian countries, where working groups (networks) have developed and are exchanging information, there has been seen an increase in the quality of services for deafblind people. "Often, questions come up that are very specific and can best be answered by an interdisciplinary team, especially by one with experience to draw from," said Dr. Andrea Wanka, Deafblind Specialist at the St. Francis Foundation (Stiftung St. Franziskus) in Schramberg, Germany. Soon, however, this absence of a network for German-speaking professionals will come to an end with the start of an EU-sponsored project. Through the DACH Initiative (Deutschland (D)-Austria(A)Switzerland-CH), which brought together German, Swiss and Austrian professionals, a survey was developed to create an overview of the services available to deafblind and dual sensory-impaired people in these countries. However, because people at the administrative level were not involved, a sustainable structure was not created. This will change, though, with a new two-year project called "PropäK" (an abbreviation of the German for 'professionalization of educational concepts'). "Now we have the chance to build an effective network for German-speaking professionals," said Andrea Wanka excitedly. Because PropäK will also include a Dutch partner, it will be supported by the EU as a cross-border partnership program for life-long learning (Leonardo da Vinci). Participants expect this interdisciplinary exchange to lead to meaningful improvement in the lives of people with deafblindness and dual sensory impairment, as work with these complex disabilities requires specialized knowledge and skills.

The St. Francis Foundation's program in Heiligenbronn, the deafblind facility of the German state of Baden-Württemberg, will undertake the organization of the project. Dr. Andrea Wanka, a teacher and deafblind specialist and director of the project said, "We all confront the same challenges and now we will be able to confront them together."

The partners in the PropäK project are:

- The German deafblind agency Taubblindenwerk in Hannover and Fischbeck
- The Blind Institute Foundation (Blindeninstitutsstiftung) in Würzburg, serving people with deafblindness and dual sensory impairment in the State of Bavaria
- The Austrian organization for deafblind and severely vision- and hearing-impaired, ÖHTB in Vienna, which provides consultation throughout Austria
- The Tanne Foundation in Switzerland, which provides deafblind and dual sensory impairment services in Langnau am Albis
- The Royal Dutch Kentalis Foundation, with facilities in the Netherlands

Included in this project, in addition to these international deafblind specialists, are the organizers who took part in the initial meeting in Heiligenbronn in the Black Forest. Guests at the conference included representatives from Oberlinhaus in Potsdam, where work with deafblind people in Germany began 125 years ago, as well as Dr. Marleen Janssen, a professor at the University of Groningen in the Netherlands. Dr. Janssen's department offers the world's only masters-level program in "Communication and Congenital Deafblindness". Several graduates of this program are participating in the PropäK project. "We are really quite proud of this European project," said the director of the Heiligenbronn foundation Michael Wollek. "People with special needs require special services," he said, in support of professional deafblind services. Referring to the emergence of the project, Roland Flaig, director of disability services in Heiligenbronn said: "Propäk is a concrete step in making the vision of a better network into a reality."

Under the direction of Andrea Wanka, conference participants discussed their ideas and wishes for the project, shared the work of their respective agencies and determined the next steps to be taken in the project. Among the goals of the project are: development of a sustainable network, the translation of relevant literature, the establishment of a central database, networking with academic institutions, and the establishment of standards for diagnostic criteria and for educational curricula. The next project meeting will take place in Vienna in December, 2012.

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Note: Press release translated by Jim Witmer

## **Remembering Peggy Freeman**

**Peggy Freeman, MBE 1918 – 2012**

### **Co-founder of Sense**

Peggy Freeman, MBE, sadly passed away in a Nottingham hospital over the weekend, following a short illness. Aged 94, Peggy was one of the parents who co-founded the National Deafblind and Rubella Association in 1955, the organisation which later became the charity Sense.

Peggy is survived by her four children, sons Ian and Robin, and daughters Ann, who lives in Australia, and Bunty, who is deafblind and lives in a Sense residential home in Birmingham.



Peggy received an MBE in 1970 for services to deafblind people for her role in co-founding Sense. The Group began with ten founder families and assets of just £2.5s.0d (£2.25). Today, Sense is the UK's largest voluntary-sector provider of services to people with both sight and hearing difficulties. It employs over 3,000 staff and meets the needs of thousands of dual-sensory impaired people from babyhood to old age.

Gillian Morbey CEO, Sense and Sense International and President of Deafblind International said, 'Although small in stature, Peggy was huge in courage and determination. At a time when people thought deafblind children couldn't be educated or live full lives Peggy battled, not only for her own daughter, but what has become the whole Sense family. Peggy made a deep impression on everyone she met and many deafblind people and their families owe Peggy a huge debt of gratitude. She is our last great 'trooper' from the early days of Sense and will be sadly missed'.

Peggy Freeman contracted Rubella in 1954 just before becoming pregnant with her fourth child, Bunty. Doctors assured her that her baby would be alright but Bunty was born deaf, blind and with heart problems. Peggy had no one to turn to for help until a teacher of deaf children introduced her to other parents of deafblind children. Peggy met another parent, Margaret Brock MBE, whose son was similarly born with Congenital Rubella Syndrome and together they formally set up the first parents' Rubella Group in 1955. Peggy was the Group's very first secretary. At the time, those with dual disabilities were neither recognised nor provided for. The Group fought for the provision of all deafblind children and pioneered Sense homes – places where deafblind people are supported with ongoing education, vocational training and leisure skills, allowing them to lead a full and meaningful life.

Up until recent years, Peggy was a regular speaker on matters of deafblindness, not just here in the UK, but also on the international stage. Even at 85 years old, Peggy flew to Canada to support Deafblind International at a conference in Canada "It is difficult to believe that a minute virus so small it can only be seen with a microscope of great magnitude, could cause impairments the vision and hearing of child even before it is born. It is also unbelievable that when a few families with rubella got together in 1955 they should start an association that in time would grow to become as successful in all fields concerned with the care of deafblind people as Sense is today.

These years have seen many changes in society and these are reflected in the changes at Sense. Changing attitudes followed a growing awareness and understanding of the needs of people with disabilities."

Paying tribute to her, Gini Bartlett, a Sense Trustee, said "I simply don't know what mothers like me would have done without Peggy. I first knew her over 45 years ago when I needed support for my son Ian who was deafblind following my contracting Rubella during my pregnancy. From the very beginning I was so impressed by how supportive she was. She was truly kind and happy to share her knowledge with me personally. I am truly indebted to her as are so many thousands of deafblind people who have received support from the organisation Sense. Peggy continued to be

amazed at the growth of Sense the awareness of deafblindness throughout the world . It is an incredible legacy she leaves behind and she will be sadly missed. In 1996 Peggy authored “Good Sense” a history of the charity. She wrote in the foreword “I wish to thank Peter who was still with me when I began writing this history of Sense and who shared all those years with me. Also the members of Sense who have worked with such dedication. Above all my thanks go to Bunty and all deafblind people. To serve them has given a purpose to my life.”

Gillian Morbey  
CEO Sense and Sense International  
President Deafblind International

### **Free software available for deafblind people**

Software developer Ulrich Greve advised Dbl that he has provided his latest software program “Summsen” available free of charge for deafblind people. This program enables deafblind people to read and write text via different vibrations felt through computer stereo speakers. The target group is deafblind people who do not have Braille knowledge or cannot afford this technique due to cost reasons. Check out website [www.tichnut.de/summsen](http://www.tichnut.de/summsen) for more information.

### **Tenth Anniversary of Vaccination Week in the Americas**

#### **and the First World Immunization Week**

This year marks two milestone events in public health: the tenth anniversary of Vaccination Week in the Americas (VWA), and the first ever World Immunization Week (WIW). In the Americas, over the last ten years, VWA has grown to become the largest multinational health in–itiative in the Region, thanks to the political commitment of governments and the dedication of the Region’s health care workers. The objectives of Vaccination Week are: 1) to advance equity and improve access to vaccination for people of all ages through outreach to underserved and marginalized communities; 2) increase vaccination coverage of all antigens to prevent disease outbreaks; 3) raise awareness on how immunization saves lives; 4) to maintain the topic on the political agenda; and 5) to promote the transition from child to family immunization. More than 365 million children, young people, men, women of childbearing age and older adults have been vaccinated as a result of activities conducted under the framework of VWA over the past nine years. In 2012, under the slogan: “For you, for me, for everyone. Get vaccinated”, countries and territories have planned to target more than 44 million people across the age spectrum for

vaccination against a wide range of diseases; 45 countries and territories in the Region have committed to celebrating this milestone initiative in 2012.

Dbl announces the 16th Dbl World Conference will be held in Romania in 2015. The Dbl Secretariat recently advised Sense International that the joint application from Sense International UK /Sense International (Romania) to host the 16th World Conference on Deafblindness has been accepted. The 2015 conference will take place in Bucharest, Romania. The timing has yet to be determined.

The conference organizers will be supported by a range of Romanian deafblind stakeholders, including national disability networks such as Reninco; NGOs; universities working in the field of deafblindness such as the faculties of Psychology and Educational Sciences in the Universities of Cluj and Bucharest; government ministries; and parastatal organisations such as the National Council for Disability.

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 are also enthusiastic about hosting the World Conference in a post-communist era country. It will be an opportunity for Sense International and the Romanian Government to demonstrate to an international audience the significant transformation that has occurred towards disability in the public policy arena since the Ceausescu era.

Finally, hosting the conference offers the opportunity to share successful models of practice in the context of a resource-poor, middle income European country. We believe this experience will have resonance for many Dbl members in Central & Eastern Europe, in former communist countries, and in Latin America and Asia.

In the coming months we shall be developing our business model further, working closely with the Dbl and establishing a local planning committee comprised of local authorities, businesses, church leaders, Ministry of Education representatives, and key members of the deafblind community. Watch for further information from Dbl through the website ([www.deafblindinternational.org](http://www.deafblindinternational.org)) and facebook ([www.facebook.com/dbiint](http://www.facebook.com/dbiint))

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## Secretariat News

### Meetings

At the Secretariat we were pleased to coordinate the ManCom meeting that was held in Lund, Sweden in early November 2012. The meeting was hosted at the Scandic Star hotel where the 9th ADBN conference took place. Following the ManCom meeting several ManCom members participated in the conference and were very proud to represent Dbl on that platform.

### Dbl Treasurer

In Sweden we were sad to say farewell Ton Groot Zwaafink as Treasurer of Dbl. We take this opportunity to thank Ton for his innovation and dedication to Dbl over the past few years and for leading the Treasury so professionally. We will miss Ton and wish him the very best future. We were pleased to welcome Frank Kat from Kentalis as the new Dbl Treasurer. Frank hit the ground running at the ManCom meeting and it was very apparent he will be an asset to Dbl. Welcome Frank!

### Conferences

#### ADBN

Congratulations to the ADBN organizing committee for hosting an exceptional conference. The program was thought provoking and sparked stimulating discussions amongst the delegates. Logistically the conference ran very smoothly and the hosts were innovative in their approach to every detail. Many friendships were formed and old ones rekindled. There was a memorable rendition of some ABBA hits and they even had the delegates sending Tweets on Twitter to spread the word and generate interest. Well done!

#### 2nd Joint Asian Conference of ICEVI & Dbl

This exciting conference will be held in Ahmedabad, Gujarat, India from 5th – 7th April 2013. The theme of the conference is “Towards an Inclusive Tomorrow”. Please visit the website: [www.icevidbiasia.org/index.html](http://www.icevidbiasia.org/index.html) for information regarding the program, registration and accommodation options.

#### Dbl European Conference

To avoid any inconvenience and for a better organization regarding your stay in Lille, the conference hosts decided to bring forward the dates of the conference due to the “Fair of Lille”. Please note the new dates for the conference are 24th – 28th August 2013.

With only nine months to go until the Dbl European Conference we are pleased to be assisting the local planning committee in circulating information. We encourage you to visit to conference website [www.dbilille2013.eu](http://www.dbilille2013.eu) to learn about the program, topics, themes and pre-conference options. On the website you will also find information for registration and abstract submissions.

#### Dbl World Conference 2015

We received two excellent bids to host the Dbl World Conference 2015. The chosen host will be announced early in 2014!

### 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. Membership renewals will be sent out early in 2013 and we look forward to welcoming back current members for another year. 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](mailto:secretariat@deafblindinternational.org)

### What's Coming Up?

Following the ManCom meeting (above) in Sweden, there is a lot of work to be accomplished between now and when we meet again in Ahmedabad, Gujarat, India in April 2013. We will be working towards achieving many of the goals set out in the now well established Strategic Plan.

Our support of the hosts in Lille will continue and we look forward to sharing the conference information over the coming months. The Dbl Board, ManCom and Annual General Meeting will be held in Lille immediately prior to the conference and we look forward to preparing for that occasion.

### 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.

## **Dbl Appeals for Support**

Dbl relies entirely on its membership for funding to support activities, staff time and travel. We provide an important 'touchstone' for over 50 organisations worldwide working in the field of deafblindness. Without this vital help we couldn't publish Dbl Review, the only international publication on deafblindness, organise conferences or support people to attend our various activities. This work is all vital to supporting deafblind people across the world, through improving practice and supporting each other.

If you can support Dbl by donating a small sum every month, giving a one off donation or simply spreading the word, we would greatly appreciate it. Please contact the secretariat at [secretariat@deafblindinternational.org](mailto:secretariat@deafblindinternational.org) to find out how you can help.

## **DbI Board Membership 2011-2015**

### **Management Committee**

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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DbI's partner organizations, ICEVI and WFDB have observer status on the DbI Board:

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