



Denise helps Nuno with the Happy Birthday song

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

DbI Review appears twice yearly, the two editions are dated January 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 DbI.

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

DbI Secretariat
PO Box 143, Burswood
WA 6100, Australia
Telephone (08) 9473 5422
Facsimile (08) 9473 5499
TTY (08) 9473 5488

Editor

Stan Munroe

Design

Geoff Dunn

Distribution and DbI Membership

DbI Secretariat

DbI Website

Stan Munroe and Secretariat

Editorial Office

CDBA Office, 2652 Morien Hwy,
Port Morien, NS, Canada B1B 1C6

Tel: 902-737-1453

Fax: 902-737-1114

Email: munroes@seaside.ns.ca

Website: www.deafblindinternational.org

Cover: Denise helps Nuno with the Happy Birthday song.

A message from the President

Dear friends and colleagues,

They say, life begins at retirement; we shall see!

If people concentrated on the really important things in life, there'd be a shortage of fishing poles!!

I will be retiring from my role as President of DbI at the World Conference in Sao Paulo in September and I am planning on doing plenty of fishing! I have enjoyed every minute of my eight years as President; made particularly special by all the people I have met along the way. Being President has allowed me to see the world, but more importantly it has enabled me to get to know so many wonderful, dedicated, passionate people over the years, including those who are deafblind, their families, significant others in their lives and professionals working in this field.

DbI is a network organisation, with groups of people from around the world working together to share and develop specialist knowledge and practice. I feel proud and lucky to have been part of this exciting organisation.

I started working with deafblind people in 1973 and in 1978 I attended my first IAEDB (now DbI) conference in New York. It was an experience that was to change my life. Since then I have enjoyed four years as Vice President and now



eight years as President of DbI. I have been involved in many different projects and networks with people from all over the world

DbI has grown bigger over time but it has not lost the family atmosphere which makes it so special.

We are now entering a time of change with a new President and Vice Presidents to be chosen. I know that DbI will be able to manage this time of change and transition with all the energy and passion that the members always put into everything they do.

Even though my President's role will be over, my commitment to DbI and deafblindness is not. So expect to see me around.

Finally, thank you everyone for being so dear and important to me and so dedicated to the development of knowledge and sharing of practice through DbI. Please stay in touch and if you feel so inclined, join me by the lakeside!

William

LAST COPY DATE FOR YOUR NEWS: 14 OCTOBER 2011

Editorial

Dear Friends,

This edition of the Dbl Review makes for a great informative summer read. You will be inspired by the excellent feature articles scattered throughout this edition. For me as a parent of an individual with congenital deafblindness, the opening article on olfaction comes close to home. I can relate to incidences that confirm my son's memory of familiar smells helping him recognize people he had not seen for a time or pleasant food treats like his grandmother's baking.

You will be touched by the story from Vula about the rescue of a beautiful little girl from the Amazon region of Brazil who was going to be sacrificed because she was deafblind. Hats off to the family who is determined to raise her and seek out the best resources for her education. There is another great story, again from Brazil, about Denise who bravely decided to change the direction of her life and move to northern Brazil to help a boy with CHARGE Syndrome.

There are many other special stories about people who are deafblind achieving such 'first's' as: the first Norwegian woman with this disability to run the New York Marathon; the first to open the day's trading at the Toronto Stock Exchange, and the first to throw out the ceremonial first pitch at a professional baseball game. This brief review would not be complete without mentioning Alex from Guatemala trying his hand at art or the young girl



scouts from Perkins with their cookie sales project. Also, take a look at the students in Sharon Grassick's classroom in Perth Australia, doing Tai Chi.

Time is speeding by as we close in on the XV World Conference scheduled for Sao Paulo, Brazil, September 26-October 01. If you haven't registered yet, please go to the conference website to register. I have a special plea to members and colleagues to support this excellent event in Brazil. The organizers took on the planning for this event with very short notice, and they are working incredibly hard to make this conference a success. I know you will not be disappointed with what is in store for you in Sao Paulo! The folks there are very experienced in organizing conferences, so you will be in for a wonderful event.

Some may think this is just a regional conference, considering that many of the presentations will be from South America. Dbl organizes its conferences in different parts of the world for local or regional organizers to promote their accomplishments to the international community. Conference hosts also take on these events as an

(continued on page 23)

Contents

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

Articles

Scents that make Sense	Page 4
Sign Chi: signing a way to relaxation and stress reduction	Page 12
Lessons of character	Page 14
New resource in Latin America	Page 16
Message from WFDB	Page 17
Helen Keller International Award	Page 52
Deafblindness and Mental Distress	page 61
Norwegian woman runs NYC marathon	Page 64
CHARGE Syndrome in Italy	Page 66

Network News

Employment, CHARGE, Outdoor, ADbN, Communications, Siblings, Rubella, Tactile Communication, EDbN, New Network Proposal	Pages 46-51
---	-------------

Country News

Australia, Brazil, Canada, Colombia, Guatemala, Ireland (p. 44), Romania, Spain, Venezuela	Pages 18-41
--	-------------

Conferences and announcements

Dbl PreConferences	Page 11
Dbl Conference Program	Page 42
ADBN Conference first announcement	Page 44
Dbl European Conference first announcement	Page 45
Sense UK Chief Executive	Page 54
Director of Perkins International	Page 55
Ahimsa celebrates 20 years	Page 56
Book – An Exceptional Fellow	Page 58
Book – Dangerous Pregnancies	Page 59
Device – Screen Braille Reader	Page 59

Dbl News and Membership

Dbl ManCom travels to Singapore	Page 60
Report from Dbl Vice President	Page 68
Dbl Conference Committees meet	Page 69
News from the Secretariat	Page 70
Membership information	Page 71-72

Scents that make sense

...examining the possibilities offered by using different odours to support learning with children who are multi-sensory impaired

The Seashell Trust, Manchester, is working with PZ Cussons (UK) Ltd to understand more about the ways that scent might be used effectively as part of the learning process with deafblind students. Anne Gough, from Seashell Trust, and Kate Williams, Creative Perfumer at Seven Scent, describe the early work....

About Seashell and PZ Cussons and the background to the partnership

The Seashell Trust runs a special school for children aged 3 – 19 years of age and a college for young people up to 25. It offers day and residential specialist provision for those with sensory impairments and severe or profound learning difficulties and significant communication difficulties, including ASD. For each child having difficulties achieving their potential within a traditional classroom setting, Seashell Trust provides a fully integrated service with highly qualified professionals and support staff, specialist facilities and high staffing ratios.

PZ Cussons in the UK is part of a leading international consumer products group, working in 10 countries, which also has its own Fragrance House, called Seven. The organisation has a committed approach to the development of local community partnerships and charitable initiatives.

Kate Williams and Anne Gough

The Background

Five years ago Anne Gough made a change to the way the curriculum had been organised in the Seashell Trust school. After some pilot studies, she introduced individualized education programmes (IEP's) that focused on each child's individual needs. It was immediately clear that the children taught using this approach and working with the modified national curriculum, made significantly better progress in communication, independence and physical development compared to a more classroom-based style.

A wide range of communication methods are used at the school including intensive interaction, on-body and hand-under-hand signing, British Sign Language, Sign Supported English, objects

of reference, pictures/photos of reference, symbols and text. Learners, who have not yet begun to interact in a meaningful way with the environment, require additional sensory input and consistent routines to help them begin to anticipate events. So teachers at the school are always looking for innovative ways to support the children's development.

This project was born out of observing some of the children already using their sense of smell to help them to identify people, places and objects. The questions were asked about how multi-sensory impaired children use their sense of smell and whether olfactory cues could improve the children's understanding and ability to make choices.



Our sense of smell

Our sense of smell differs from our other senses being the only sense to send information directly to the brain. Information received through our other senses is first analysed in the body via neurons and the central nervous system to identify what to attend to and what to ignore (Brown, 2007). Olfactory information has a direct path to our limbic system, which is why smells trigger strong emotions and memories. There is evidence that memories triggered by smells, rather than by sights or sounds, often link to the early stages of life, suggesting that olfactory memories are laid down earlier (Willander and Larsson, 2007).

It also seems that memories triggered by odours are more emotional and more immediate than those linked to sounds or sights. The sense of smell is linked to our recognition of family and friends and our ability to respond to others' emotions (Aglioti and Pazzaglia, 2011). It affects social interaction and attraction in number of ways (Stockhorst and Pietrowsky, 2004).

There is some evidence that sense of smell is linked to motor planning and in one study it was found that smelling fruits or sandwiches triggered grasping actions. (Tubaldi et al, 2010).

Research with people born blind suggests that they are better than sighted people at odour detection (noticing that a smell is present) and odour awareness, especially regarding smells related to people. It is likely that blind people attend more to odour as a way of identifying people



Scent-embedded disc

(Beaulieu-Lefebvre et al, 2011). Different studies in this area show varying results, perhaps because of different methods used in research.

An account by an adult with acquired deafblindness describes the range of information he gets through smell as his only possibility of gaining distant impressions of events happening around him. In the same account he writes of his pleasure walking through a store selling different kinds of food and of information he gets from odour at different stages of familiar journeys (www.deafblind.com).

When different information is available through our different senses, usually vision takes precedence; occasionally hearing (Aglioti and Pazzaglia, 2011). When the combination of similar information is received from several senses simultaneously (for example, smelling smoke, seeing flames, hearing fire alarm), the efficiency of our actions and reactions increases.

Sounds promising ... but a warning

So, it could be concluded that emphasising the use of smell, as well as touch and residual vision



and hearing, is therefore likely to be helpful to multi-sensory impaired (MSI) learners; but we need to be careful. David Brown (2007) describes some hazards of deliberately stressing olfaction: smells can't be 'put away' or 'turned off' and fragrances which are not integral to the activity may confuse students. Some students may be hypersensitive to specific smells. In addition, odours tend to be unpredictable (affected by air currents for example) and transient (Stockhorst and Pitrowsky, 2004).

One fundamental issue is that some students with MSI have impaired sense of smell. This is particularly likely in students with CHARGE syndrome (Brown, 2007).

In summary the research on olfaction suggests that:

- the sense of smell has a direct link to memory and emotions
- the sense of smell underpins much of our social interaction and awareness of others
- people with visual impairments and blindness may develop more acute responses to olfactory information
- the sense of smell tends to work as a background sense rather than foreground sense, and



Choosing...



smelling...



drinking a milkshake

information gained through smell can be overridden by information from other senses

- odour/scent can be used to add to information received through other senses
- using scents with students with MSI needs to be carefully planned and be based on smell and function being linked.

Using Scents with MSI Students

Seashell Trust is very fortunate to have links to PZ Cussons, and through these links the ideas in relation to olfaction were discussed. Kate Williams is a Creative Perfumer who has a special interest in fragrance communication and how olfaction links to memory and emotion. Her role is to create fragrances for all different kinds of consumer products and experiences. Initially, Kate spent a lot of time observing specific children; recording how they made use of 'smell' in the context of their multi-sensory modes of learning.

Jason

The first student Kate worked with was Jason who had always used smell as his major sense. Jason was twelve when Kate met him. He is highly motivated by visual stimuli (e.g. lights, spinning toys and movement), but his initial reaction to everything is to smell it. Jason has a multi sensory impairment affecting his vision, hearing and communication. He has a bi-lateral sensori-neural hearing loss compounded by auditory processing difficulties. Jason's vision is significantly impaired through the condition called Peter's Anomaly. He also has nystagmus and a diagnosis of glaucoma. Jason's communication was limited to the here and now. He had no interest or recognition of pictures and signs and made

very few responses to sound. He did not understand their purpose.

Jason identifies people through their odour and reinforced his understanding of objects, food and drinks using his sense of smell. In Kate's words, "I saw that he experienced and explored the world in much the same way I did – by using his sense of smell."

Kate developed some fragrances that Jason could use in his daily routine to make choices of his favourite drinks. The fragrances were applied to photographs and Jason began to make the connection between the picture and what it represented. The fragrances, appearing to act as a bridge to a gap in his understanding, motivated him.

Jason is now fourteen and no longer requires pictures to be fragranced to recognise them. As Jason began to understand what the pictures stood for, some written words were introduced with a fragrance attached. Using the food and drink fragrance was highly motivating. He learnt to recognise written words of some of his favourite food and drinks. He now uses pictures and words to communicate his wants and needs in different contexts and recognises some words without the fragrance. He can follow a handwritten shopping list independently.

Adding Scent to Objects of Reference

It is easy to recognise that Jason is exceptional. It was felt that his responses supported the idea that other students with MSI could benefit from using smell and we wanted to continue to explore how it could be used effectively.

Children with MSI are difficult to study systematically because of the interactive effects of different impairments, inconsistencies of behaviour and difficulties of

knowing what information a child is receiving (Murdoch, 2004). It is also important to protect children who cannot anticipate or understand novel experiences from potential distress.

Our study

We decided to observe some students more formally, identifying how well fragrances worked for them and which factors affected response. A simple study schedule was developed, using video filming, to observe and record the ways in which a specific group of children made use of 'smell' in the context of their learning calendar and in particular in association with locating a room where, typically, that smell would be functional.

What did we do?

Familiar staff working with the children, introduced familiar objects of reference during their everyday routine. The only change was that certain objects of reference (OR) had a fragrance added. This same fragrance was added to the room destination for the activity represented on the OR.

Film was used to record the OR being presented and the student's response each time. We then analysed the film to look for possible factors affecting response.



Hazards described by Brown (2007) were minimised or avoided:

- Fragrance pens were used to add the scent to the Objects of Reference to minimise 'leakage' of smell
- The fragrance in the room was functional and was part of the activity in the room: e.g. massage
- Students were carefully observed so that any hypersensitivity or unhappiness would be picked up. None was noted and the evidence suggested that students enjoyed the scent.

Two examples of the children in the study

Matthew

Matthew is 13 years old and communicates non-verbally. He has complex needs which include: cerebral palsy, developmental delay and optic atrophy. He is registered blind. Matthew is beginning to understand objects of references representing his daily activities.

Matthew was filmed responding to an object of reference for one of two rooms used in his normal daily teaching routine. The object of reference for one room sometimes had the fragrance that was used in the room added to it; the other had no fragrance associated with it. Matthew was



Time for massage

encouraged to feel and smell the object of reference which was then attached to a bag around his waist. We filmed his interaction with the OR and the staff member, his decision on which way to turn and his subsequent journey. This was repeated daily over several weeks, allowing for absences due illness and holidays.

Matthew's emotional state varies which affects his ability to respond to information. Sometimes he may need reassurance above all else, and seeks close contact rather than information. On some occasions Matthew was distracted by conflicting information from his other senses. Light shining through the window, other sights, sounds and air currents caused by people passing by or opening a door, all distracted him.

On some occasions, however, Matthew was able to respond to the scented OR. For example:

Notes from video analysis

21-4-10: Matthew was keen to mouth/smell the OR. He stood quickly in response to the words 'Let's go'. The OR had not been placed on his bag as he was keen to hold on to it to smell and mouth it; he then turned and walked in the right direction...The smell would be on his face and around his nose from licking



and smelling the OR; it may be that this reinforced the smell and helped him to continue walking to the Snoezelen room without being distracted and needing further reminder.

Matthew also seemed to find the scent soothing, especially later in the study when the scent became more familiar. For example, on a day when he was initially quite distressed and seeking contact with his staff member:

She picked up the OR and passed it to Matthew. He took it and immediately took it to his face, pressing it against his nose and lips, and then held it in his right hand and flapped it. His support worker (LSA) touched his nose and said 'Smell'; he took it again to his face and stilled and smiled.

Anna

The second example is Anna; she is 14 years old, communicates non-verbally and relies on routines. Anna has a diagnosis of a profound hearing loss with epilepsy. She has difficulties processing visual information and has developed a good understanding of objects of reference for motivating activities such as dinner. However she has

been less successful to date making the association of objects if they are referenced with other activities.

Anna is open to the same distractions as Matthew, tending to follow other people who walked past her or entering any rooms with open doors. Once Anna became familiar with the scent, however, she seemed able to be able to make more use of it:

Notes from video analysis

14-07-10: Anna walked up the corridor, holding the Object of Reference in her left hand, with her support worker (LSA) behind. Anna stopped at the milk trolley and swayed; the LSA paused and started to walk towards Anna, who lifted the Object of Reference to her nose and smelt it without a prompt from the LSA. She then walked a few more steps and smelt the Object of Reference again swaying and making a buzzing sound. Anna carried on walking up to the shelf at the pivot point, where she turned and looked at the LSA and paused; she then turned back around to face the main door. A member of staff came through the door, pushing a student in a wheelchair, and

walked towards Anna. They walked past her away down the corridor. Anna then smelt the Object of Reference again and swayed. She then turned to the right and continued walking; the doors were open to both the left and right of Anna. Anna walked through the open door on the right to the Snoezelen room and stopped and turned to look for the LSA.

Observations of both Matthew and Anna suggest that scents may be able to help students engage and maintain interest in an activity, and that they may also evoke an emotional response from the student. Both the examples described here happened in a busy school, with competing distractions. Further work could be done to understand the effectiveness of this method when the student is in a controlled situation.

Sensory Theatre and the use of scent to recall events and feelings

A second idea was to use scent in a multisensory environment, so the 'sensory theatre' was chosen. The theatre comprises a multi-use

specialist room with a computer that links video images with 'surround sound' and lighting effects to create the overall atmosphere. A multi sensory experience can be developed so students can re-visit real life experiences and be encouraged to recall the events, and communicate to others what they did and how they felt.

Theme: Seaside

Students who had visited the seaside recently, used the theatre to recall the experience. The experience was supported by odours and sensory props related to the event. An ozone fragrance pervaded the room to create the seaside atmosphere, with fans blowing to create the sea breeze. The sound of waves and gulls screeching and calling played through the speakers. Sand and water, seaweed, shells, pebbles, crabs and fish were the props

Remembering bonfire night

which included the items the students had collected on their visit and each had its own unique fragrance!

How did the students respond? When the door was opened to the sensory theatre for the first time, the smell of the beach was so strong, that two of the children who had bare feet on their trip to the sea removed their shoes before entering!

Theme: Bonfire Night

November is a time for a traditional occasion when people in England make a large fire outside, enjoy fireworks and eat very specific things such as gingerbread, treacle toffee and sausages cooked in the embers of the fire.

So, the theatre housed a bonfire party with the smell of the fireworks and bonfire. The theatre was quite dark, like night, with autumn leaves on the floor.

A bonfire (made from sticks surrounding a fan and orange and yellow streamers blowing upwards to look like flames) created a strong smell of burnt wood coming from the room. A visually impaired student recognised the smell and sounds on opening of the door and knew what would happen later – noisy fireworks - so he sat outside the room on the floor with his hands over his ears!

Theme: Christmas

A pine fragrance was used to enhance the smell of the Christmas trees, together with a spicy orange and clove fragrance to create a Christmas atmosphere while the children made Christingles for the Assembly. Some of the children really noticed the scents when they were enhanced in this way and showed more interest in the stimuli - often stilling while smelling and then smiling.





Making Christingles



What have we concluded so far?

While the work so far is exploratory, we are finding out how to bring together the perfumer's art and our detailed knowledge of students with MSI to give greatest benefit to the students. This work is teaching us how to use scents to provide additional information as part of each child's development as communicative individuals. Observations so far suggest that using scent can help some students to engage with experiences. For some, it has been possible to begin to use olfactory information, in conjunction with other sources, to support locational learning. For many, it appears to add to enjoyment in a range of situations and in recalling experiences.

Appropriateness and safety

Everything we do must be carefully thought out and child-centred. Particular characteristics of smell, and ways in which individual students react, must drive the approach. With any novel approach caution is required.

The need for safety is obviously important as fragrances created for the perfume and cosmetics industries have to meet safety standards. The fragrances used in this study were specifically created for the students, and had to be safe and robust to meet their needs. Seven, the perfumer, involved a toxicologist during fragrance development to ensure fragrances would be safe for students when they came into contact with skin, were licked or mouthed or accidentally ingested.

The next stage

The next phase of the project is being planned in partnership with, and support from, PZ Cussons. The intent is to build on students' experiences, focusing on using scents in 'choice-making', not easily available through other channels. The work will concentrate on the students' ability to anticipate and communicate choice; taking that learning and generalise it to the wider world.

Anne Gough, Deputy Head Teacher, Seashell Trust
Anne.Gough@seashelltrust.org.uk
www.seashelltrust.org.uk

Kate Williams, Creative Perfumer, Seven Scent
(www.sevenscent.co.uk)

References

How do deafblind people cope? Retrieved from www.deafblind.com/coperg.html in March 2011.

Aglioti, S.M. and Pazzaglia, M. (2011) *Sounds and scents in (social) action*. Trends in Cognitive Sciences, 15,2, 47-55.

Beaulieu-Lefebvre, M., Schneider, F.C., Kupers, R. and Ptito, M. (2011) *Odor perception and odor awareness in congenital blindness*. Brain Research Bulletin, 84,3, 206-209.

Brown, D. (2007) *The sense of smell - the olfactory sense*. Dbl Review, July-December 2007, 4-8.

Murdoch, H. (2004) *Early intervention for children who are deafblind*. Educational and Child Psychology, 21, 2, 67-79.

Stockhorst, U. and Pietrowsky, R. (2004) *Olfactory perception, communication and the nose-to-brain pathway*. Physiology and Behavior, 83, 3-11.

Tubaldi, F., Turella, L., Pierno, A.C., Grodd, W., Tirindelli, R. and Castiello, U. (2010) *Smelling odors, understanding actions*. Social Neuroscience, 6, 1, 31-47.

Willander, J. and Larsson, M. (2007) *Olfaction and emotion: the case of autobiographical memory*. Memory and Cognition, 35, 7, 1659-1663.



PRE CONFERENCES

“FAMILIES”

- Families challenges
- The role of parents organizations
- Experiences

SPEAKERS

Stan Munroe (Canada) – Aurea María Soza (Argentina) – Ricard Lopez (Spain) - Susana María de Aráoz (Brazil)

DATE AND PLACE: September 24, 2011, Time: 9:00 to 17:00. Sao Paulo, Brazil

“EVALUATION OF DEAFBLIND AND MULTI SENSORY DISABLED PEOPLE”

- Evaluation of children and young adults with sensorial impairment
- Learning through the observation of children and identifying sensorial channels used by them
- Individual evaluation process

SPEAKERS

Jan van Dijk (Netherlands) – Rick van Dijk (Netherlands) – Catherine Nelson (USA)

DATE AND PLACE: September 25 – 26, 2011, Time: 9:00 to 17:00. Sao Paulo, Brazil

“TACTILE COMMUNICATION NETWORK”

- Landscape of Touch
- Tactile Communication
- Competent Tactile Partners

SPEAKERS

Bernadette Van Den Tillaart (USA) - Barbara Miles (USA) – Paul Hart (Scotland) - Gunner Vege (Norway)

DATE AND PLACE: September 25-26, 2011, Time: 9:00 to 17:00. Sao Paulo, Brazil

REGISTRATIONS:

Please send the registration form to cisinando.lima@ahimsa.org.br
Limited spaces for participants



Sign Chi: Signing a way to relaxation and stress reduction



Sharon Barrey Grassick, Deafblind Education Team Leader
 WA Institute for Deaf Education, Western Australia sbgrassick@gmail.com

As a Tai Chi practitioner for over 5 years, the personal benefits for me have been enormous, including stress reduction, relaxation, increased energy and improved balance and posture. This newfound sense of well-being encouraged me to become a Tai Chi Instructor about 2 years ago.

One day while planning for my students who are deafblind, it suddenly hit me – so many aspects of Tai Chi that could be adapted to benefit the

children I was working with! Since that revelation I have explored ways that Tai Chi can be adapted for children who are deafblind or have balance issues, eg. CHARGE Syndrome. Although targeted at children with sensory issues, these techniques can be adapted and enjoyed with any child, regardless of abilities or disabilities. Part of Tai Chi's beauty is that it can be done just about anywhere and can be done with the whole family.

Thinking outside the square

Children and adults who are deafblind have unique and varied abilities and disabilities. There is no quick fix or strategy that will work with all. As educators, we must constantly be thinking outside the square, to find ways that can interest, encourage and involve individuals with sensory disabilities, who can often be difficult to motivate. At the same time, we are increasingly including children with disabilities into mainstream schools and activities. Finding activities that can be equally motivating to students with and without sensory disabilities is a challenge.

Tai Chi offers a new perspective

on opportunities for inclusion for children who are deafblind, including children with multiple disabilities. Tai Chi is safe. It has the least documented injuries of any sport, including Yoga and Pilates. Where some Yoga moves tend to put pressure on upper body, wrists and shoulder joints, Tai Chi focuses on weight shift. Tai Chi is a mental and physical form of exercise, often referred to as 'moving meditation'.

Individuals with deafblindness frequently experience stress and difficulties with self-regulation. Research into the benefits of Tai Chi is plentiful and well documented, with most all documentation referring to reduced stress and improved ability to focus and concentrate. Websites are included in references at the end of this article, which contain a great deal of information regarding Tai Chi and its benefits to individuals of all ages and abilities.

Fun Chi

In 2009, modified Tai Chi exercises were introduced to a class of grade 2 students, which included one child with CHARGE Syndrome. Basic Tai Chi moves were selected and adapted so that the child with CHARGE could do them successfully, but with enough challenge so there would be benefits.

Some of the elements that made this experience so successful are as follows:

- Number One: A receptive school and classroom teacher! (Thanks Barry and Tracy!);
- Names for this 'special Tai Chi' were suggested by the children and names then voted upon; Fun Chi was the clear winner;
- Students also voted for the sign name for Fun Chi (the sign for 'fun' followed by the Tai Chi bow);
- Students were involved in re-naming various moves, if they wished, and the class voted upon suggestions, eg. The warm-up exercise of waving arms became the 'Octopus Dance'; the Shibashi move 'Painting the Rainbow' stayed the same, as they liked that name and majority vote ruled;



Left: Ocean surge

- Some move names changed each week to include a particular student's name, eg. 'Watering the Lotus Garden' became 'Watering Ann's Tomatoes'; students enjoyed having their names included;
- Students made their own Fun Chi badges, which they wore for each session;
- Each session, Fun Chi Assistants were chosen, to lead the following session, based upon each weeks participation; assistants stood up front with me and led the group (this was highly motivating for most of the children);
- Sessions were videoed periodically; students loved seeing themselves on the screen;
- Fun Chi was performed for the school community during a whole school Assembly – the students did a fantastic job and the audience was genuinely impressed, as indicated by a number of comments afterwards about the unnatural silence and calmness throughout the performance. Generally this group is asked several times during assembly to quiet down... not necessary that day.

A demonstration of Fun Chi was given at the CHARGE Syndrome Foundation World Conference, All that Jazz, held in Chicago in July 2009. Children and young adults with CHARGE, who joined in, really enjoyed it!

Sign Chi

In 2010, Fun Chi was reintroduced to the grade 3 class, which included the child with CHARGE and many of the same classmates, but with some new students. A greater effort was being made in grade 3 to encourage classmates to learn sign language so, in order to promote this concept, Fun Chi evolved into Sign Chi. The Auslan (Australian Sign Language)



Making butterflies

alphabet and numbers were used in Tai Chi moves, as well as signs that reflected class themes and interests.

Tai Chi moves have been adapted to incorporate signs related to the movements, eg. In 'Greeting the Morning Sun' instead of simply raising and lowering arms, the sign for 'sun' is made at top of the movement.

These students are now in grade 4 and still enjoying Sign Chi. Recently the class visited an aqua marine center and the language experience included learning signs for various sea creatures; these signs were then incorporated into Tai Chi movements. This became Sea Chi. The students are now learning about the planets and space. You guessed it – they are now learning space signs through Space Chi!

Knee Chi

A Kindy group of 4 and 5 year-olds are now enjoying Knee Chi. The adapted Tai Chi moves are made with me kneeling on a special Knee Chi cushion, to enable eye contact to be made with the children, without them straining their necks to see me.

Additional advantages

Some of the additional advantages of Fun Chi and Sign Chi are as follows:

- Can be done anywhere, anytime – inside or outside
- No special clothes or footwear required (bare-feet are great)
- No equipment to buy
- Easy to learn, with repetitive exercises.

Research

Research is currently underway at Central Michigan University (CMU), which is investigating the potential benefits of Tai Chi, specifically with children with CHARGE Syndrome. A DVD is being produced in Perth which demonstrates the basic elements of Fun Chi. This DVD will be offered for use in the CMU research, to be sent to parents of children with CHARGE who will then give feedback to enable measurements to be made in regard to any improvement in balance, sleep and/or behaviour.

This research and active demonstrations of Fun Chi and Sign Chi will be presented at the upcoming CHARGE Syndrome Conference to be held in Orlando Florida in July 2011.

References:

- Barrey Grassick, Sharon (2009). Fun Chi: De-stress for Kids. Presentation in Proceedings of 'All that Jazz' Conference of CHARGE Syndrome Foundation, Chicago.
- Barrey Grassick, Sharon (2010). Sign Chi: A Unique Way to Learn Sign Language: Presentation in Proceedings of 'B in CHARGE' Conference of CHARGE Syndrome Conference of Australasia, Fremantle Western Australia.
www.taichiatthebeach.com;
www.worldtaichiday.org

Lessons of character

Perkins Deafblind Program's Girl Scout troop teaches confidence, humanity
Reprinted from The Lantern, Spring 2011

Watertown, MA – Troop Leader Sharon Stelzer looked around the room for a volunteer. Moments from now, the local Watertown Girl Scouts would walk through the door of the Hilton Building on the campus of Perkins School for the Blind, and she needed someone from the Deafblind Program to lead the joint meeting through The Girl Scout Promise.

Slater – a 12-year-old girl who is normally on the shy side – jumped up without hesitation, and began signing the words.

“She really showed her leadership skills,” said Stelzer, who is also a teacher in the Deafblind Program. “It was so great, because normally she needs a little coaxing.”

Slater's volunteerism was also a sign of courage, confidence and character – all qualities encouraged

and celebrated by the Girl Scouts of the USA. Such are the goals emphasized every week by the members of Troop 71984. These girls – each with a variety of challenges including vision, hearing and cognitive disabilities – are eager to earn their merit badges and strengthen friendships. They wear their green vests to weekly meetings, pay dues and practice life skills that will serve them well into

Katriana and Alicia at their cookie sales counter





Slater practices her sales techniques using the alphabet board

adulthood.

"We work on social goals and communication skills," said Stelzer. "For our girls, it's best to learn through routine. They come in and put their vests on. We do an attendance board. We pass the can around and they pay their dues, so they can work on fine motor skills like putting coins in the can and passing it to the next person. And we always do the Girl Scout Promise."

And, of course, there are those decadent cookies. The girls sell Thin Mints, Peanut Butter Patties and more to students, teachers and staff across campus. In

addition to raising money for activities, the process is an opportunity to improve vocational skills and work on social interaction. Most of the girls are non-verbal and use a variety of alternative communication methods to interact with their customers.

"One girl has a new iPad she's been using to sell cookies. One of the girls has an alphabet board," said Stelzer. "It's a safe way for them to practice in a small setting."

Perkins has been home to various Girl Scout and Boy Scout troops for decades. The first official Boy Scout troop was meeting regularly

as early as 1952. It is unclear when the first troop for girls was organized, but they have been an active part of Perkins student life for years. The current troop, which Perkins believes is the only one in the country whose members are deafblind, continues to represent the Girl Scouts in proud fashion, participating recently in several activities that have a direct impact on the community including a clothing drive and a collection of canned goods.

"It's having the girls participate in small ways, and having them know they're doing something for other people," said Stelzer.

New resource in Latin America

For people with deafblindness, visual impairments and additional disabilities, their families and professionals

Founded in 1829, Perkins School for the Blind is an educational center for students with blindness, deafblindness or visual impairments with additional disabilities.

Perkins's basic mission is to support this population to achieve as much independence as possible. Key to this support is teacher training and the provision of assistance to many colleges to develop or expand their special training programs.

In 1989, Perkins established a comprehensive International Program to support the education of children who are blind or

visually impaired with additional disabilities living outside of the United States. The primary focus of Perkins International is to develop capacities at local regional and national levels to support sustainable and independent educational services. Perkins International currently is active in parts of Asia, Africa, Eastern and Central Europe, Latin America and the Caribbean.

Until recently, Perkins International did not have a web site that could offer Spanish speaking people in Latin America the opportunity to locate valuable information on these subjects, give

their opinions and exchange ideas. For this reason the idea came forth to create a Perkins web site in Spanish. This new site, www.perkinsla.org, became operational in October, 2010.

The site consists of a "Central page" where one can read about the mission and history of Perkins International. This is also a place which features life stories from particular individuals, families or professionals who wish to share their experiences in relation to deafblindness and / or visual impairment with additional disabilities.

Other sections of the website include:



"Projects", which presents information from each of the Perkins International support programs in Latin America.



"News" from different programs.

"Library", describing the main library resources available from Perkins International.

"Events and Courses", presenting the schedule of regional training programs, workshops, meetings and important program activities;

"Publications" where one can read and download articles of interest prepared by the various programs and written in Spanish or Portuguese.



"Photo Gallery" where one can see photographs and videos from programs.

"Contact us" for users to communicate with the site manager to make requests, provide comments and suggestions.

In future we hope to continue the site's growth and intend to continue adding interesting information in Spanish and Portuguese to further enrich all users in Latin America, in particularly parents and health professionals.



"Stories of Life", which describes significant aspects of the learning achievements of some children and youth.

Message from WFDB



Lex Grandia, President of the World Federation of the Deafblind, reports:

General description of WFDB

The World Federation of the DeafBlind (WFDB) is a representative organisation of persons with deafblindness. It is not a school or an institution. Through this organization, people who are deafblind communicate by e-mail. In addition to virtual communication, WFDB organizes a General Assembly every four years, during which time democratic elections are held and decisions are made. The President, or other designated persons, can represent the members worldwide speaking on their behalf, promoting the rights of persons with deafblindness. This process looks quite easy, if only we knew how complicated it has become.

Call it training

WFDB organised a training course for the four Executive Board members from the African Federation of the DeafBlind (AFDB), in Pretoria, South Africa at the beginning of March 2011. Martin Kieti from Perkins International acted as a teacher as did Joe Morrissey from CBM and Thomas Ongolo of the Secretariat of the African Decade of Personswith Disabilities. Even this president of WFDB took one day to be a teacher! I am happy to have the university qualifications for that.

Our wide ranging discussion included the following: the mission and vision of AFDB; the role of the different board members; democratic structures and decision-making process; the need to have relevant action plans; the need to have people with the right skills in the right places; financial management and cooperation with other partners. It was not a training session as such; we did not make exercises observing our decision-making processes. We shared information, experiences and knowledge. Lack of information is a big problem for many persons with deafblindness worldwide. More training, or was it education, is definitely needed.

Education in politics

On a daily basis, WFDB works closely together with the International Disability Alliance (IDA). Three staff members from IDA are following the work of the Human Rights Council, the United Nations committees of the eight Treaty bodies, especially the Convention on the Rights of Persons with Disabilities (CRPD), and preparation of many Human Rights Council Resolutions and thematic studies. The goal is to get the rights of persons with disabilities mentioned in all those documents and reports.

WFDB needs to be alert and raise awareness to all those policy



Lex Grandia

makers about the rights and needs of persons with deafblindness. The same is going on with the whole system around the UN General Assembly and United Nations ECOSOC in New York. Is this just awareness raising or is it educating politicians, because they just don't know? Although WFDB has been fighting to get the right to education and life-long learning spelled out in Article 24 of the Convention on the Rights of Persons with Disabilities, there still remains missing information around how education and life-long learning for persons with deafblindness could be done best.

WFDB is at the moment I am writing this article, involved in the preparation for a high level Ministers meeting on inclusive education at the United Nations in July, 2011.

For Dbl's future consideration, WFDB welcomes collaboration with Dbl to develop a policy paper on education of persons with deafblindness, as a basis for our collective works at the international level.

Australia



Mike Steer

Deafblindness in Australia: Report on the 8th National Conference

Delegates from all over Australia, and from as far away as Italy, the United Kingdom and the Republic of Botswana, attended the recent conference in Melbourne to consider new ideas, directions and solutions. The Australian Deafblind Council (ADBC) and sponsors Able Australia provided an informative and comprehensive program to identify core issues, showcase new technology and discuss strategies for improving outcomes for people with dual sensory impairment. Perhaps the most valuable part of the conference was the emphasis on finding ways for people with deafblindness to reduce isolation and achieve greater social and economic participation. It is clear that mainstream services, government and the community need to take time to listen to people with deafblindness to better understand how needs can be met. As a direct result of the conference, ADBC President Sven Topp has started his own blog; which is available at <http://dbaustrian.blogspot.com/> Conference proceedings are also available via the ADBC website at <http://deafblind.org.au/>

News from ABLE AUSTRALIA

Deafblindness numbers in Australia could reach one million by 2050

Able Australia, one of Australia's major service providers to people who

are Deafblind, has warned that the prevalence of deafblindness will increase as Australia's population ages. Access Economics data produced for Deafblind Awareness Week predict that about 1.1 million Australians will have the combined disability by 2050. Able Australia spokesman Stefan Grun indicated that combined sight and hearing loss is a forgotten disability that needs more government funding. "We can only provide, on average, three hours of support to our clients a week," he said. Some of our clients are completely reliant on our caseworkers to have contact with the outside world; to do their shopping, or their banking, to have a meal at a restaurant. "It's a very isolating existence to them if they can't have access to services such as ours."

Disability Groups Unite for a National Disability Insurance Scheme

A coalition of groups representing people with disabilities, families and service providers has come together to push for the introduction of a National Disability Insurance Scheme (NDIS). Frustrated by years of neglect and underfunding by successive governments, the coalition has decided that a strong collective voice is required to ensure that the needs of Australians with a disability and their families are finally placed on the political and public agenda. The coalition has established a campaign fund to ensure the public understands the need for

such a scheme. The goal of the campaign is to promote awareness of the NDIS and a greater understanding of the opportunities it will provide for people with disability and their families.

The National Disability Insurance Scheme represents a once in a lifetime opportunity to change the lives of people with a disability and their families in this country," said Lesley Hall, spokesperson for the National Disability and Carer Alliance. For too long, Australians with a disability have been reliant on limited government support or charitable handouts. They have not received the support they require to be full, active contributing members of the community," she said.

Celebration

The Royal Institute for Deaf and Blind Children celebrated its 150th anniversary on October 22. The Institute established Australia's first school for Deaf children in 1860 with seven students. These were soon joined by a similar number of children who were blind. The Institute's famed Alice Betteridge School was named after an early deafblind student who was later widely known as "Australia's Helen Keller". In 2010 more than 900 children across Australia are enrolled in RIDBC programs.

Employment Issues

The Commonwealth Government's Department of Education Employment & Work Place Relations (DEEWR) is currently consulting with disability

organisations on a new national contract for Disability Employment Services. The current contract expires in July 2012 and the Department is seeking input on ways to improve the current model. The Australian Deafblind Council (ADBC) met with Department officials in January. Members Carla Anderson, Meredith Prain and ADBC's Executive Officer Alisa Wills attended and discussed the significant challenges faced by Australians who are Deafblind and who wish to obtain employment.

Recreation

The annual National Deafblind Camp will be held on the weekend of 1–3 April 2011 at the Phillip Island Adventure Resort in Victoria. The camp resort has a variety of activities for deafblind people to enjoy including canoeing, archery, swimming in the pool and visiting the beach, and bush walking. This year campers will take bus trips around and off the island, for example to local wineries. There is an outdoor pool and spa and plenty of space to walk around or just sit back and relax. The camp cost is A\$150.00 for deafblind holiday-makers, and A\$20.00 for volunteers. For more information please contact Emely McCord at Able Australia on 1300 225 369 or emely.mccord@ableaustralia.org.au

Training Events

A Deafblind Awareness Training event was offered in Hobart, Tasmania, in December 2010. A similar event was offered in Perth,

Western Australia on 4 February, 2011 followed by an assertiveness training event for people with deafblindness on 5 February. Both sessions were held at Senses Foundation in Perth. Let's Connect training sessions are planned for Darwin, Northern Territory on 1 and 2 July, 2011. For information contact Meredith Prain meredith.prain@ableaustralia.org.au

Improving Access to Emergency Services Call Numbers

Access to emergency services is expected to be made easier for people who are deaf, hearing impaired or speech impaired. Senator Conroy, the Minister for Broadband, Communications and the Digital Economy made the announcement at the Comms Day Summit in Sydney in the middle of 2010. He intends to establish an SMS emergency service for people with disabilities. "I have asked my Department to address these implementation issues as a matter of priority," Senator Conroy said. Currently, TTY services for access to emergency services are available to people who have deafness or a hearing or speech impairment by calling 106, but this service cannot accept SMS messages. A technical feasibility study into the provision of SMS services was conducted by the Australian Communications and Media Authority in 2009.

Conferences

International Mobility Conference 2012, 'Mobility through the Ages, Up,

Over and Down Under' will be held in Palmerston North, New Zealand on 13 to 17 February 2012. The call for abstracts opens in February 2011 and closes 30 April 2011. To register your interest, please see the conference website at <http://www.imc14.com/page.php?1>

Peak Disability Body Calls for Overhaul to Disability Supports

The Australian Federation of Disability Organisations (AFDO) has welcomed the Commonwealth Government Productivity Commission's draft report on a Long Term Disability Care and Support Scheme, and has called for a comprehensive overhaul of the disability support system.

"At the moment Australians with disability are falling through all sorts of gaps," said Ms Lesley Hall, AFDO CEO. "Some are shut into hospitals and nursing homes because the funding isn't there to provide them with supports at home, which in many cases would be cheaper. Others rely on family and friends to give them support, which wears down their social networks. In some cases the lack of appropriate supports means people with disability are abused but they're afraid to leave because there's nothing else."

Project: Let's Connect

Able Australia Services received funding from V.V.Marshman Trustees for a three year project to run Deafblind Awareness Training for service providers and Assertiveness Training for people with deafblindness in

Australia continued

**Australia
continued**

each capital city in Australia. The project commenced in July 2009 and since that time workshops have been run in 5 States with only one State and one Territory remaining. Guest speakers have attended the Assertiveness Training sessions from State based Equal Opportunity and Anti Discrimination Commissions to discuss legal rights and processes for making complaints. Feedback from the training has been very positive with a number of participants asking for

the training to be run on an annual basis. To date 102 service providers and 42 people with deafblindness have attended the training. Funding has included the cost of interpreters and note takers for people who are deafblind. These costs have been reduced through the support of various organisations around Australia including The Forsight Foundation, Senses Foundation, Deaf Services Queensland and Guide Dogs Tasmania. These

organizations have provided training rooms free of charge and staff to support people with deafblindness during the training sessions.

For further information about the project contact Meredith Prain meredith.prain@ableaustralia.org.au

Meredith Prain
Speech Pathologist /
Let's Connect Project Officer
Able Australia Services
www.ableaustralia.org.au
03 9861 6202
TTY 03 9882 6786

Australia's Oldest Deafblindness Agency Celebrates Sesquicentennial Anniversary

European settlement of Terra Australis, the Great Southern Land, commenced in 1788 when a British penal colony was established on the continent's east coast. From this colony, the nation of Australia was born. Back in England, as Law (1922) has described, Australia was considered little more than a far-flung outpost of Great Britain, one of the several targets of its social hygiene policies. Charity had

a major role the way the new colony cared for disabled and disadvantaged people. In 1813, the Benevolent Society of New South Wales was formed by a group of evangelical Christians. Between 1813 and 1818, some 250 individuals received support from this society. With regard to the education and welfare of children who were blind, or deaf, little if anything constructive occurred between 1788 and the 1860's. On 22 October 1860,

downtown Sydney. That day marked the origin of the Royal Institute for Deaf and Blind Children.

With the help of several prominent figures of the time, the school, with residential facilities, was officially declared a public institution on 15 October 1861. In the first year it had moved to 368 Castlereagh Street, then in 1868 moved to Ormonde House in South Head Road, Paddington, a central Sydney suburb. In 1872, the school moved to large, purpose-built premises at Newtown (now Darlington), where it remained for the next 70 years. These premises, now a part of Sydney University, are still known as the 'Institute Building' although they were purchased by Sydney University in 1961.

Royal Institute's original building in Newtown



Thomas Pattison, a deaf migrant from Scotland, commenced classes with seven other deaf children in a converted house in

**Australia
continued**

In 1961, RIDBC moved to North Rocks, where it is currently located. In addition to its present location in the tree-lined northern Sydney North Rocks site, RIDBC has a school at North Parramatta and educational services at Penrith in the Hunter region between Sydney and Newcastle to the North.

Together with changes of location, RIDBC has changed its name several times since its founding in 1861. These changes reflect the pervading philosophy of education for children with disabilities of the times and the links between RIDBC and the wider community

In chronological order, the following are some of the major milestones in the Institute's history.

1869 - The first blind children to receive specialist services are enrolled. The Institution is named The New South Wales Institution for the Deaf, Dumb and the Blind.

1873 - Samuel Watson begins evening classes for deaf adults. He believes that if children grow up within a group, segregated from the mainstream of society, they will need continuing support in dealing with the new experiences they face as adults in the wider community.

1880 - The Public Education Act makes general education "free, secular and compulsory" but makes no provision for deaf and blind children. The Institution undertakes a steady campaign for

compulsory education for all. Despite many appeals, the government stands firm on its decision not to pass such an Act. It will take until 1944 for education to be compulsory for deaf and blind children between the ages of six and eleven years.

1905 – 1910 A rubella (German Measles) outbreak in 1905 results in a huge influx of children being enrolled in RIDBC in the years 1909-10. The relationship between deaf blindness and a rubella-infected pregnant woman is not known at the time. Sir Norman Gregg discovers this 40 years later.

Alice Betteridge, RIDBC's first deafblind student, enrolls in 1908. Alice attends the school until 1921. She is the first deafblind student to receive an education in Australia.

1911 – Superintendent Harold Earlam, a progressive educationalist, introduces the notion that deaf children could be taught to speak. He also extends the use of Braille within the school and ensures the school has the most suitable Braille books and the latest Braille equipment.

1948 - Student numbers reach 242. A second rubella epidemic four years' earlier means that almost half of these children are in the junior age range. The Department of Education assumes responsibility for the education of blind children at the recently established Wahroonga School.

1957 - Her Majesty Queen Elizabeth II honours the

Institution by conferring the prefix "Royal" in its title. The name becomes The Royal New South Wales Institution for Deaf and Blind Children, having the word 'dumb' deleted.

1963 - The North Rocks premises of the Royal New South Wales Institution for Deaf and Blind Children are officially opened by the Governor of New South Wales, Sir Eric Woodward.

1965 - The Institution enters into a partnership with the Department of Education to provide the first service for deafblind children in the Southern Hemisphere.

1967 - A preschool for deafblind children is established; a parent counseling service is provided and additional sporting and recreational facilities are built.

1970 - The Parent Counseling Service is expanded to embrace the families of blind preschoolers. A program for deafblind children who do not meet Department of Education standards is opened. The students in this unit, once labeled 'uneducatable', make great gains and reach goals once thought impossible.

1973 - A long-term joint research project between Macquarie University and the Institution commences. The focus of research is on communication, speech and language comprehension. Throughout the early 1970s, the Institute turns its attention to the specific

**Australia
continued**

educational needs of multi-handicapped children. Following intensive investigations both within Australia and abroad, a pilot program commences which leads to the establishment in 1974 of the first school in Australia for multi-handicapped blind children in. Known as The Special School for Multi-Handicapped Blind Children, the school provides accommodation as well as medical, educational and therapeutic facilities.

1978 - The first computerized Braille production unit in Australia is established at the Institute. Today, the Institute continues to produce Braille, large print and tactile diagrams for students.

1980 - Increased enrolments and demand for the specialist services provided by the Special School for Multi-Handicapped Blind Children necessitated major extensions to the school. They were officially opened by the Prime Minister of Australia, The Right Honorable Malcolm Fraser.

1985 - A separate Junior Department in the Special School for Multi-Handicapped Blind Children is established. John Berryman is appointed Chief Executive of the Royal Institute for Deaf and Blind Children. Mr. Berryman retired on 31 March, 2011 and was succeeded by Mr. Chris Rehn, recently CEO of Cochlear.

1990 - The Special School for Multi-Handicapped Blind

Students is renamed the Alice Betteridge School.

1991 - The Tingira Centre in the Hunter Region is opened. This is the Institute's first major regional undertaking and provides a base for Early Childhood Services. It offers both preschool and day care programs on a reverse integration enrolment basis. A 'Homestart' service is also conducted from the Centre.

The RIDBC Itinerant Teaching Service is established. Through this service, students attending independent schools who are hearing impaired and vision impaired, are provided with specialist support from trained teachers of the deaf or of the blind.

1992 - In response to community needs, the Institute establishes the Roberta Reid Centre, a preschool for deaf children and hearing children of deaf parents for whom Australian Sign Language (Auslan) is their first language.

The Royal Institute for Deaf and Blind Children and The University of Newcastle completed a Memorandum of Agreement to create the basis for Renwick College – a centre for research and professional education to be operated by the Institute in affiliation with the University.

1994 - A reverse integration Early Childhood Centre for Children with sensory disabilities is established at Glenmore Park near Penrith. Renwick College is launched and new facilities are opened by His Excellency

Rear Admiral Peter Sinclair, Governor of New South Wales. Seventeen students commence in the Master of Special Education (Sensory Disability) program.

1997 - The first 13 graduates of Renwick College receive their Master of Special Education (Sensory Disability) awards from the University of Newcastle.

1998 - Early intervention and preschool services for deaf and hearing impaired children are consolidated into a new department, Early Childhood Services – Deafness and Hearing Impairments. RIDBC services are more widely promoted within non-English speaking communities.

2002 - Jim Patrick Audiology Centre opens at North Rocks.

The Dorothy Paul Family Resource Centre opens for families of children with vision impairment.

2004 - The Welwyn Centre opens. This is a base for services for children with impaired hearing and their families.

2005 - The Royal Institute for Deaf and Blind Children reaches a new record: over 600 children and families are enrolled in its services.

2007 - RIDBC Teleschool is launched, providing vital services and support to rural and regional Australian families with children who are hearing or vision impaired.

2010 - A new RIDBC Renwick Centre is opened by Her Excellency, Governor Marie Bashir. The Royal Institute for Deaf and Blind Children celebrated its 150th Anniversary. RIDBC now supports over 950 children and their families across Australia and provides vision and hearing screening to thousands more.

The 500th graduate of programs operated by RIDBC Renwick Centre receives the degree of Master of Special Education. More than 140 students are now enrolled in RIDBC Renwick Centre/ University of Newcastle degree programs.

RIDBC is also the major sponsor and home for the Australian Childhood Vision Impairment Register (ACVIR). The Register has recently started to collect data on Australian children with vision impairment aged 0-18 years. This is the first time research of this sort has been done. Incoming data are already beginning to provide a picture of childhood vision impairment not previously

available. Families of children with vision impairment are invited to register using the website hosting the Register called the VI Family Network (www.vifamilynetwork.org.au). Families are also informed about the Register by their supporting agency and their child's eye health professional. Once consent has been provided, families are asked for details on their child including their visual capability, low vision needs and general health status. The family also chooses to allow their child's eye health professional to contribute data including an eye and vision diagnosis and the child's vision status.

Families of registered children are offered membership in an online parent community which is hosted by the website. The website also gives access to low vision resources and upcoming low vision related events. There are to date 380 children registered, of whom approximately 4.2% of children are deafblind. The most common eye and

vision disorders in these children include Cortical Vision Impairment, CHARGE Association, Cortical Vision Impairment and Norrie's disease.

This article is submitted as a tribute to an organisation that for the past 150 years has been a pillar in service provision to Australian children and young adults with deafblindness.

Authors: Sue Silveira, JAFF Senior Research Fellow & Mike Steer, Senior Lecturers, Royal Institute for Deaf & Blind Children North Rocks, NSW, Australia

Australia continued

References

Law, A. (1922). *How the Church came to us in Australia*. Melbourne: Imperial Press.

State Library, New South Wales. (2010). *The Benevolent Society*. Retrieved 28 February, 2011 from: http://www.sl.nsw.gov.au/discover_collections/history_nation/religion/charity/benevolent.html

Sydney Architecture. (2010). *Institute Building, 1870-72*. Retrieved 04 May, 2011 from: <http://www.sydneyarchitecture.com/UNI/UNI-073.htm>

Editorial (continued from page 3)

opportunity to explain to local government officials and funders about deafblindness and the need for better services. The last conference held in South America (Cordoba, 1995) was a catalyst for the eventual flourishing of deafblindness programs throughout Latin America.

Finally, thanks to all the contributors who responded to requests for material for this edition of the magazine. I trust you will enjoy this edition; your comments are most welcome.

Stan Munroe

Letter to the Editor

Dear Stan,

Thank you for your warm and thoughtful message. I am touched with your consideration.

As you mentioned, and as you may watch on TV, we (in Japan) are suffering from the earthquake, aftershock, Tsunami and an accident of a nuclear plant. Fortunately the region we are living is not affected, but still they are suffering from the results the earthquake has brought. We are not sure how many people with deafblindness are suffering,

because there are a lot of invisible deafblind people in Japan. We are still working on what we can do for them.

We are very pleased and proud of being on the cover of the last edition of the magazine. I am very moved because someone up north in the sphere is caring about us.

Thank you again.

Sincerely,

Akemi Fujii

April 17, 2011

Brazil

An Intervenor in the Amazon

By Denise Teperine Dias



There are many challenges for professionals working to benefit the lives of deafblind people in Brazil. It is a country of vast dimensions, divided into 5 regions where each one is like being in a whole different country due to so many differences regarding food, culture, festivals and traditions not to mention climate and vegetation.

In 2006, Grupo Brazil, the network that supports deafblind and the multiple sensory impaired people in Brazil, began a two year outreach program in different regions of Brazil. Staff came to understand the different realities faced by deafblind people and their families living in various locations of the country.

On one of the outreach trips, I was part of a group that went to Manaus, Amazonas. There I had the opportunity to meet a family who was dealing with the developmental implications of a child who was diagnosed

with CHARGE Syndrome. When I first met this 4 year old boy Nuno, something touched me. I stayed there, watching him hit his head on the floor; with all the people around him not knowing what to do to help him. The suffering of the family was real. They had already looked for all the best doctors in the country to help their son deal with his self injurious behavior.

After returning to São Paulo, I continued to have contact with that family by telephone. Recognizing that this was not being of much help for the family of the child, I made a life changing decision three months later. I decided that I would go to the Amazon to work with Nuno and help the family establish a school for Amazonian children, like Nuno, with severe disabilities.

In 2003, I had the opportunity to travel to Canada to attend the Dbl World Conference. While there I visited several congenital deafblindness programs where the Intervenor model was practiced. Since that time I couldn't stop thinking about my desire to do something similar here in Brazil. I realized that our reality here in Brazil is quite different from Canada to undertake on such an initiative. To do this in an Amazonian would be even more challenging.

Taking the big decision to move!

I knew I was alone in taking the risk to take this step. I would be leaving behind my solid career as a teacher in a public school to live in a very different environment. I would have to live in a climatic region of high temperature and humidity, with the worry of contacting a tropical disease. Despite that, I was constantly thinking about Nuno. I worried about his difficulties, especially his health, as he was being regularly admitted to the hospital because of acute respiratory problems. I didn't hesitate any longer; I made the decision to sell everything and move to Manaus! My desire to share my knowledge was greater than my apprehensions.

I traveled a long way by plane, because the only way to get to Manaus is by air or a 17 day trip by boat. It was also a personal voyage of finding a new way of life. It would be a work totally different from everything I had done before. I had been a teacher for the blind and for the deafblind, where I had to work with different students for just a few hours a day. This would be an entirely new working situation, where in addition to learning an individual's family situation, I would be taking on the additional responsibilities of dealing with a child with CHARGE Syndrome – all day long.

I arrived in Manaus in

Clapping hands to the Happy Birthday song



January 12th, 2008. When I met Nuno after first arriving, he appeared more “isolated” than when I had met him three months ago. He was still on the floor self-stimulating and showing self-injurious behavior. He didn’t know how to communicate. The people around him didn’t know how to interact with him either. He didn’t understand what was happening around him. His fragile body was incapable of bearing his own weight, so he was always being carried around, being fed with baby bottles without any solid food. It was then I noticed that the situation would be more difficult than I had imagined.

One of the difficult questions I had among many others was how could I develop Nuno’s communication with all the other problems created by CHARGE syndrome. An additional complication to Nuno’s challenges was that he was being over-protected. He was a child totally dependent on other people and never allowed to satisfy his biological needs by himself. So here was a human being without any initiative and he had no expressive communication.

My first thoughts were that Nuno had to be taught about his environment and how to be aware of and accept people around him. How could he be stimulated through physical contact and through toys and games to awaken, in him, the desire to know the world around him? In addition he had to develop means of expressive communication.

Where to start the intervention process?

In the first months I focused on the aspects related to his non-interaction with others, and to other aspects related to his development. I was also seeking a way that would ensure that everyone involved with Nuno would change the way they saw him. I wanted to encourage them to have a more positive attitude and to invest more of their time more towards building an individual. So I started to search everything in the literature about CHARGE syndrome. What could be done to stimulate him and strengthen his self-esteem? How could we think about his future?

When I learned that these problems were common to a child with CHARGE Syndrome, I saw it necessary to broaden my knowledge about specific aspects of development and its emotional aspects.

For me to get Nuno to the point of using his hands as a receptor and expression channel, it was necessary to go through an intense program where the routine, the anticipation of events, people and activities, were structured in such a way to give him a sense of the world around him through his tactile sense.

Individuals with multiple impairments obviously have more difficulties keeping involved with the social interaction and exploring their environment. These abilities can be taught to individuals as part of a routine program focusing on communication. As an Intervenor or mediator, I



invest a lot of time and effort to do these daily activities which seem so simple and mundane yet they become so critical in creating communication.

Using O&M arriving at school

In closing, the opportunity to work full-time (10 hours a day, 6 days a week) with a child has given me the reason to believe even more strongly that when a child has severe problems, their functional, communication and emotional development can be positively improved if there is someone to take on the function of an Intervenor. In my opinion, when a person takes the time, effort and dedication to help a child in a high risk group, this is most rewarding because one sees the child developing, getting stronger physically and emotionally, becoming ready to overcome any boundaries.

Brazil
continued

International Seminar on Inclusive Education, Manaus, Brazil



Vula
Ikonomidis

This past February, 2011, Stan Munroe from Canada and Jude Nicholas from Norway were invited to participate in a two-day International Seminar on inclusive education in Manaus, the capital city of the state of Amazonas. Resources on disabilities in this part of the country are scarce including specialized services and professional training.

In 2006 Grupo Brasil, in a partnership with the Ministry for Education,

provided an 80 hour training course on deafblindness and multisensory impairment to about 40 professionals in the northern region of Brazil, which includes the states of Acre, Amapá, Amazonas, Pará and Rondônia.

The only services established for this disability population in Amazonas state is in a School for the Deaf where we visited this past February. Five deafblind teenagers attend this school. While the staff are in competent in their job, it is not nearly enough. In Amazonas State there is no early intervention program, just to give an example of the reality people with disabilities face there. When a diagnosis or some specialized treatment is required, the individual and family must travel to São Paulo City in the southeast, a

four hour trip by plane if the flight has no stopovers.

Thus, it was of extreme importance and promoted great interest in the region with the visit and talk from Stan Munroe and Jude Nicholas. Stan addressed issues related to the Late Manifestations of Rubella Syndrome and the need for immunization. He also gave testimony of the excellent and most needed work of Intervenors in Canada, illustrated with a beautiful video from George Brown College, in Toronto. Dr. Nicholas explained the importance of tactile cognitions, pointing out the essentials of communication and along with a description of CHARGE Syndrome.

These seminars also followed by a presentation from Shirley Maia, President of Grupo Brasil. She gave

International presenters surrounded by Manaus seminar participants from Parintins Island, Amazonia





Deafblind young lady with her family and school teachers in Manaus meet with seminar presenters

an update on the situation of Rubella and CHARGE Syndrome cases around the country, explaining the needs and major difficulties that people with these conditions experience. Another speaker was Denise Teperin Dias who moved to Manaus from Sao Paulo to be an Intervenor for a boy with CHARGE Syndrome. She addressed the child's problems and lack of services in the region. She spoke also about the successes she had

accomplished with this boy and his family. She has also organized a support network online where she advises parents of children with CHARGE Syndrome in Brazil.

The seminar attracted over 250 professionals from different cities in Amazonas state, including places that take up to a week travelling by boat to get to Manaus. A lady representing the Secretary of Education of the region opened and closed the event describing the

importance of this seminar towards new regional actions. She expressed thanks to Stan Munroe and Jude Nicholas, for taking the time to help disseminate valuable information to such a distant and isolated place as Manaus, bringing warmth and support that is worth more than gold.

Vula Ikonmidis
Educational Coordinator
AHIMSA, Sao Paulo Brazil
Vula2004@hotmail.com
Website: www.ahimsa.org.br



Jude Nicholas addressing seminar in Manaus

Brazil
continued

Deafblind baby Indian girl rescued from sacrifice in Brazil



In the Northern state of Pará a family that runs a foundation that helps and fights for the rights of native Amazonian Indian tribes found out about a disabled baby girl who was to be 'sacrificed'. According to the tribes in this Amazon region, it is not up to "white man" to interfere with the Indian values and traditions. For example, in this particular tribe if twins are born, they

believe that one is evil and the other is good. Since there is no way to know who is who, they sacrifice both babies. In the case I am going to discuss, Bia had a twin brother who was born premature and died at birth. Whether she was a twin or not, Bia was going to be sacrificed because they noticed she was also deaf and blind. The family from the foundation found out about her and took steps to adopt her and bring her to Belem, the capital city of Pará State.

This same family owns a private school and a college in Belem. This school of over 850 students practices inclusive education, where more than 150 students have a disability. However, this is the first time they will receive

a child with deafblindness. The staff was most concerned about how to organize a program to welcome this girl who is now two years old. When this family heard about the International Seminar taking place in the Amazonas state, they invited the group to come to Belem in Pará state, near the estuary of the Amazon River, and two hours by plane.

The school staff had prepared a full day of activities for the group, beginning with a visit to the school where Bia was going to start attending classes. In the afternoon they gathered all personnel, including teachers and therapists, to hear Stan Munroe and Jude Nicholas speak about issues that would help them relieve doubts about Bia attending

Bia and her adoptive mother in Belem



Brazil
continued



Jude Nicholas, Vula Ikonmidis, Stan Munroe, Shirley Maia addressing school staff in Belem

this school.

In the evening they had organized a session at the college for students to hear a lecture from our visitors. Stan spoke about the importance of families and family organizations for developing services for persons who are deafblind. Jude spoke about the deafblindness disability and the importance of tactile communications. Shirley Maia also presented on the works of Grupo Brasil.

Subsequently, the Belem family scheduled a visit for the teacher, physiotherapist, occupational therapist and the baby's Intervenor to spend a week in São Paulo. The group visited Ahimsa in April to observe the various programs to take back more information for their task ahead. Hands down, Bia is a lucky star, offering charm and sweetness to all who meet her. It is rare to have so many people engaged in making

sure someone gets the most of everything. Best wishes, Bia, and may you have a happy and long life.

Vula Ikonmidis
Educational Coordinator
AHIMSA, Sao Paulo Brazil
Vula2004@hotmail.com
Website: www.ahimsa.org.br

Canada

DeafBlind Ontario Services is getting into FOCUS

Since 2003, DeafBlind Ontario Services has been conducting internal audits independently to ensure consistency and quality of services for the people we support.

In 2008, we received a grant from the Ontario Trillium Foundation to develop standards of practice in the field of deafblindness. While many developmental service agencies have such standards to guide their service, the deafblind sector did not. We partnered with other agencies who serve the deafblind across Ontario to develop these standards and tested them in two of these agencies. The result of the project is the document *Standards of Excellence for People who are Deafblind* – the first of its kind in the Province of Ontario. The 4 standards are Direct Service, Governance, Human Resources and Financial Accountability, all centered around deafblindness.

Following successful completion of *Standards of Excellence for People who are Deafblind*, DeafBlind Ontario Services partnered with 'FOCUS Accreditation to develop standards around Intervenor services and deafblindness. FOCUS is an accreditation body that understands community services and the environment in which organizations

work. Agencies that provide Intervenor Services and are seeking accreditation through FOCUS will now be required to meet these new service standards.

During this partnership with FOCUS Accreditation, we decided to take on the exciting challenge of seeking accreditation for our own organization!



Why become accredited?

In keeping with our Vision to be a leader in the field of deafblindness and delivering excellence and expertise in the field of deafblindness, DeafBlind Ontario Services will be the first Intervenor Services organization in Ontario to be accredited by FOCUS. By becoming accredited, we are committing to ongoing, continuous learning and growth. As an accredited organization, we would be demonstrating to families, funders, community partners,

and most importantly, to people who use our services, that we are dedicated to excellence and accountability.

Accreditation focuses on such attributes as: outcomes for people using the organization's services, organizational excellence, community development and accountability to internal and external stakeholders. Third party accreditation ensures an unbiased, comprehensive assessment of service quality. It identifies areas of strength and challenges; we'll take on those challenges to do better!

The process of accreditation emphasizes learning from the people we serve and from each other. DeafBlind Ontario Services prides itself on being in a continuous state of learning, improvement and change. FOCUS Accreditation standards reflect current best practices. When standards are met, people who use the services have an assurance of quality, feeling confident that the organization is committed to continuous improvement.

What is involved in the accreditation process?

DeafBlind Ontario Services formed an accreditation committee comprised of a core group of staff from all levels and positions in the

agency. The committee has been hard at work over the past months gathering and compiling information about our programs and services; identifying areas of strength and potential growth within the organization.

Once the information for all the standards are gathered and compiled, the documentation is submitted to the FOCUS Validation team for review. This would then be followed by an intensive on-site validation process. The on-site validation process will involve interviews and surveys with not only the staff at DeafBlind Ontario Services, but also with volunteers, family members, community partners, and people with deafblindness that use our services. Following the on-site validation process, FOCUS will review all information gathered and inform us of



Canada continued

the outcome. If successful, we would be granted official accreditation status for three consecutive years. We will also create a Continuous Quality Improvement plan to guide us during those three years.

We look forward to the challenges of seeking accreditation, developing our quality improvement plan; all designed to improve our

services to those who are deafblind.

Susan Manahan
 Manager, Community Engagement & Quality Assurance
 Deafblind Ontario Services
www.deafblindontario.com

CDBA National appoints new Executive Director

The Canadian Deafblind Association, National Office, appointed Tom McFadden as their new Executive Director on January 01, 2011. Tom replaced Stan Munroe, who was the previous ED.

Tom is a seasoned association executive director with extensive management, conference/event and fund development experience in the not-for-profit health care sector.

Before coming to the Canadian Deafblind Association, Tom served as Executive Director of

a number of prominent professional, charitable and special interest /agency based organizations at the local, provincial and national levels.

In his career, Tom has participated in a voluntary capacity with community service organizations, Boards and committees, and has teaching and coaching experience at the high school, community college and university levels.

To quote Tom, in his introductory remarks from the CDBA website (www.cdbanational.com), "I am excited and enthused about



what lies ahead for the field of deafblindness as we start down a new road full of challenges and opportunities. Arnold H. Glasow once said... The trouble with the future is that it usually arrives before we are ready for it. Well, the future is now."

Canada
continued

Two special firsts

Headline Deafblind Awareness Month in Ontario

June has been proclaimed as Deafblind Awareness Month in the province of Ontario for the past 11 years. This past June was arguably the most successful awareness campaign ever for the Ontario Chapter of the Canadian Deafblind Association (CDBA). There were two special awareness activities that set this year apart from years past.

First, the Toronto Blue Jays of Major League Baseball (MLB) invited CDBA Ontario to throw out the ceremonial first pitch during a regular season game. The ceremonial first pitch is a longstanding ritual of baseball where a guest of honour throws a ball to mark the start of the game.

Steffen Zimmer, a nine year

old boy who is deafblind, was selected to throw out the ceremonial first pitch. Steffen and his family use CDBA Ontario's Children's Intervenor Services. He was joined on the field by his father and older brother, each of them wearing CDBA Ontario t-shirts. Catching Steffen's pitch was the top pitcher on the Toronto Blue Jays. To the delight of the tens of thousands of fans, Steffen threw a one bounce pitch into the glove of star pitcher Ricky Romero. Nearly 200 people from the CDBA community (individuals who are deafblind, family, staff, supporters) were in attendance that night to witness Steffen's pitch. The first pitch was a unique awareness opportunity for CDBA Ontario and an evening that the Zimmer family will never forget.

The second event was a first in Canada. On June 3rd, Julia, an individual who is deafblind, made history when she opened the market at the Toronto Stock Exchange (TSX). She is the first person who is deafblind to open the market at the Toronto Stock Exchange in its 150 years of operation. Julia was joined by senior staff and her Intervenor for the occasion.

The market opening dating back to the beginning of the modern Stock Exchange, indicates the start of the day's trading. It has now become a ceremonial action and is typically used by corporation executives and celebrities for product launches.

Before opening the market, Julia and the CDBA staff had a chance to meet executives from the TSX during a light breakfast. The executives had never met an individual



Steffen accompanied by father and older brother approach the pitcher's mound



Steffen is about to pitch



Steffen throws the ceremonial pitch

Canada
continued

Julia (centre), surrounded by representatives from CDBA and TSX, opens the morning market.

who is deafblind or been exposed to the concept of an Intervenor. Julia stole the show during the breakfast. The executives were amazed by the communication between Julia and her Intervenor and they all wanted to meet her.

Opening the TSX was the largest publicity event in the history of CDBA Ontario. In addition to being broadcast on television across the

country, a photo of Julia and CDBA opening the market was on the front page of www.tsx.ca, exposing the 1.5 million daily visitors of that website to deafblindness. Dating back to 1861, the Toronto Stock Exchange (TSX) is North America's third largest stock exchange and the seventh largest in the entire world.

It was a historic Deafblind Awareness Month for

CDBA Ontario, one that the Zimmer's, Julia and our staff won't soon forget.

Devin Shyminsky
Communications Coordinator
Ontario Chapter, Canadian
Deafblind Association
www.cdbaontario.com

Canada
continued

Jane Sayer named recipient of 1st Annual "JT Award"

Jane Sayer from Winnipeg Manitoba was named recipient of the 1st Annual "JT" award at the 9th Annual JuneFest in Toronto, Ontario on June 15, 2011.



Jane Sayer with her award

“Jane Sayer is a consumer herself who spends her days working as Executive Director of the Resource Centre for Manitobans who are Deaf-Blind and much of her free time volunteering”

Rotary Cheshire Homes Inc. and the Canadian Helen Keller Centre Inc. established the “JT Award” in honour of a great friend and leader in the field of deafblindness - Joyce “JT” Thompson. Joyce was a champion of the disability of deafblindness and consumers for over 30 years. Joyce sadly passed away earlier this year.

During those 30 years Joyce played pivotal roles in the founding of Rotary Cheshire Homes in 1992 and the Canadian Helen Keller Centre in 2001. In 2000, Joyce worked alongside former Willowdale MPP David Young to declare June “Deaf-Blind Awareness Month” across the province, and she single handedly founded JuneFest in 2003.

In all of Joyce’s work she brought Awareness to the disability of deafblindness, Expansion to the services available and ensured Involvement of consumers who are deafblind. At last year’s JuneFest, Joyce was presented with the “JuneFest Award of Excellence” to recognize the tremendous and lasting effects she’s had on this sector. This year, that award has been renamed the “JT Award”. It is meant to recognize the good work that takes place across Canada for Canadians who

are deafblind going forward.

Jane Sayer is a consumer herself who spends her days working as Executive Director of the Resource Centre for Manitobans who are Deaf-Blind and much of her free time volunteering.

As a volunteer, Jane Sayer has filled many positions with the Canadian National Society of the Deaf-Blind, the Canadian Deaf-Blind Council, the Manitoba Deaf-Blind Association and she has also acted as an advisor on the necessary accommodation needs for travelers who are deafblind with the federal Canadian Transportation Agency.

Although very dedicated, Jane is adamant that all people who are deafblind have a responsibility to advocate for themselves. As one of her nominators said, “Jane, like Joyce, is connected to people in the deafblind community across the country – everyone knows Jane Sayer and her work in advocacy. How many of us can say that?”

Rotary Cheshire Homes and Resource Centre for Manitobans who are Deaf-Blind are small corporate members of Deafblind International.

Deafblindness or dual sensory impairment?

Canada
continued

Two Canadian researchers from Montreal, Canada are inviting clinicians who work with clients affected with both hearing and vision loss to participate in a survey. The researchers are attempting to define deafblindness and its current priority issues, from the responses provided by stakeholders in the rehabilitation domain. The goal is to publish the findings in a peer reviewed scientific journal.

Participants are asked to participate either online or by contacting the researchers directly. For online participation

of the English version of the survey, participants can logon to <http://www.surveymonkey.com/s/Z5JNVFY>. Those preferring to complete the survey in Word format or with any questions can contact Walter Wittich (wwittich@ssss.gouv.qc.ca) or Martine Gendron (mgendron@raymond-dewar.gouv.qc.ca). The researchers would like the survey completed before October 7th 2011.

This project is being conducted by Walter Wittich, post-doctoral fellow and research coordinator at the MAB-Mackay Rehabilitation Centre, in collaboration with

Martine Gendron, audiologist at the Institut Raymond-Dewar, Montreal, Canada.

A protocol for this research has received approval by the Ethics Review Board of the Centre de recherche interdisciplinaire en réadaptation (CRIR-605-0311).

Colombia becomes the 100th country to ratify the UN disability convention

Colombia

On 10 May, United Nations Convention on the Rights of Persons with Disabilities reached an important milestone with the South American nation of Colombia becoming the 100th country to ratify this Convention which supports greater access for the disabled to participate in their communities.

UN Secretary General Ban Ki-moon hailed Colombia's ratification as an important milestone for Colombia and for the global community tool for inclusion and

development. Let us use this "to make concrete improvements in the lives of persons with disabilities," the Secretary General said.

Mr. Ban's remarks were echoed by Sha Zukang, the United Nations Under-Secretary-General of the Department of Economic and Social Affairs (DESA), who said he was greatly encouraged by the ratification. DESA is the UN department which serves as Secretariat for the Convention.

"This is a great

achievement by the international community in working towards a just and equitable society, based on equality and equal opportunity for all, including persons with disabilities," Mr. Sha said.

The Convention was adopted by the General Assembly in 2006 in an effort to ensure that persons with disabilities enjoy the same human rights as everyone else. Eighty-two countries immediately signed it – the highest number for a UN treaty in history.

Guatemala 'Trazos de luz' – Strokes of Light from Guatemala



Guatemala
Foundation for
Children with
Deafblindness
www.fundal.org.gt

At FUNDAL we are continuously looking for new and creative ways to create awareness about deafblindness and to raise the funds needed in order to continue providing our services. It has been a dream of ours to design a calendar that provides information about this unknown disability including the opportunity to share positive images of the children and teenagers with deafblindness. We were unable to find the perfect topic for this calendar until we discovered 'Trazos de luz' or 'Strokes of Light'.

At the beginning, the project sprung as an artistic outlet for children and teenagers with deafblindness and associated disabilities. We asked each student to

represent their feelings and experiences on paper. As usual, the students at FUNDAL proved that what seems unreachable was never so.

From the artistic description provided by each student, professional artists interpreted each of their designs through adding colors resulting in producing sixty-three artistic masterpieces for the 2010 Fundal calendar 'Trazos de luz' or 'Strokes of Light'. This project was a most successful opportunity to promote the recognition, respect and dignity of children with disabilities in Guatemala.

We have learned so much from this project. Our perspective on many things has changed greatly,

Alex enjoying nature and exploring the watercolor paper by pencil



**Guatemala
continued**

Salvador
Orellana adding
color to Alex's
design



Alex's original strokes

such as what we thought was simply taking a pencil and drawing a line. Simply stated, sketches created through a disabled child's hard work, supplemented by an artist adding color, provided a pictorial means by which each child could communicate what was in their heart.

**Diana Isabel Bonilla Sinibaldi
Arc. Salvador Orellana
Communication and Human
Development Project
Promoter**



**Salvador's painting was inspired by Alex's
enjoyment of nature**

Romania



Sense International (Romania) celebrates 10 years!

After a decade of existence, Sense International (Romania) is proud to have accomplished a series of major achievements. These include: supporting the Romanian authorities to set up the first ever services for deafblind people; having deafblindness recognised as a distinct disability by Romanian legislation, and developing ample screening, rehabilitation and educational programmes for children with multisensory impairments.

“When our work began, there were no services for deafblind people. The problems they were facing were unknown and there wasn’t even a word in the dictionary for this type of disability, let alone specific programmes for the identification or assessment of these deficiencies...” says Cristiana Salomie, director of Sense International (Romania).

The Early Intervention programme is developed in partnership with national and local authorities, kindergartens and schools. Sense International (Romania) has supported the hearing screening and visual testing of 29,550 newborn babies and very young children, ensuring their opportunity to benefit from diagnosis and counseling.

After the screening / testing stage, SI(R) has been actively involved in providing solutions to the problems identified. Since the project started, 53 children have been diagnosed with sensory impairments and began an individualised rehabilitation programme within the Early Intervention Support Centres developed by SI(R) in Bucharest, Oradea and Timisoara.

Three multidisciplinary teams consisting of 11 early intervention workers and 12 health care specialists

ensure the rehabilitation of deafblind children through a series of techniques and therapies.

The Education for Deafblind/Multisensory Impaired Children is developed in partnership with the Ministry of Education, Research, Youth and Sports. In academic year 2010-2011, 140 deafblind/MSI children have been receiving specialised educational services in 15 Romanian state special schools.

For the first time ever, a non-governmental organisation has trained, over the past 10 years, 85 special education teachers involved in the education of deafblind and multisensory impaired children. The programme provides these children with the opportunity to go to school and learn, using specific methods and techniques.

A dream becomes reality !

Spain

Dolores Romero, Chairman of the Spanish Association of Parents of Deafblind People (APASCIDE), writes ...

The first residential centre for deafblind youth and adults in Spain is now open with a second centre on the way!

APASCIDE opened its first residential centre "Saint Angela de la Cruz" for deafblind people in the fall of 2010. The centre is located in Seville, Southern Spain. The building is all on one floor, with an additional 5,400 sq metres of land adjacent to it for leisure and recreational activities.

The centre provides two services. A residential service and a day centre. The residential centre has the capacity for 17 people, the majority of whom are congenitally deafblind and

are aged between 16 and 48 years old. The day centre accommodates 28 people, the majority of whom are deafblind and people with sensory impairment with limited communication skills. The age range for the day centre is 16 to 48 years old.

The centre includes such facilities as a gymnasium, an indoor pool and SPA, an eco kitchen garden (with trees), rooms for sensory stimulation and speech therapy, and other facilities to support the development of these deafblind people. The centre also has workshops for cooking, pottery, crafts, textiles, IT, reading and writing.

The centre has a unique

design with different galleries and pathways, providing good accessibility through the placing of hand rails in the halls and rooms and a communication environment through Braille signs and different textures. The centre also features different aromatic trees in the gardens to enable these individuals to become more independent through identifying different environments in the facility.

Official opening

Saint Angela de la Cruz Centre was officially opened by Queen Dona Sofia on 26 October 2010. During the Queen's visit, she was



Queen Donna Sofia is introduced to Christina Margarita

Spain continued

Apascide group celebrates the opening of Saint Angela de la Cruz



introduced to the Centre's Director Aida Hernandez, the Chairman of APASCIDE Dolores Romero, the President of Andalusia Region Jose Antonio Grinan, and other dignitaries.

A second residential centre

The Chairman showed the Queen the plans for the next project, The Helen

Keller Centre. APASCIDE has already purchased 18,000 sq meters of land in the city of Ciudad Real, which is located in central Spain, to build this centre. The reason that this location was chosen is because it will give families more opportunity to have services closer to them.

APASCIDE, the Spanish Association of parents with deafblind people,

was founded in 1991, and develops programmes for deafblind people and their families in Spain. APASCIDE is a small corporate member of Deafblind International.

For further details about APASCIDE and its new centre, check out www.apascide.org or by email: centrosantaangela@apascide.org

Queen Donna Sofia meets the ceramic artists



Micros for Deafblindness Campaign in Venezuela



SOCIEVEN, Sordociegos de Venezuela (Deafblindness Venezuela), is launching 'Micros for Deafblindness', a communication tool using actors, artists and athletes to help increase awareness of deafblindness. Various television stations, including E-Entertainment Television, Direct TV, Conferry TV and other National TV channels, help telecast these seven short

information spots or micros. The use of these micros in the media was approved by CONATEL, Venezuela National Telecommunications Commission.

Check out the details of our awareness messages on our website and through links on <http://www.youtube.com>. To demonstrate the effectiveness of public awareness campaigns, Socieven was able to locate

709 persons in Venezuela with deafblindness during the period 2006 -2010.

Special thanks to the project promoters 'Ambassadors for Deafblindness' through the leadership of Anabella Troconis, for the production and editing work on these micros.

Maria Luz Neri de Troconis
Socieven and
www.socieven.org.

Micros for Deafblindness

What is Deafblindness?	http://www.youtube.com/watch?v=an5SETFDYco
Levels of Deafblindness	http://www.youtube.com/watch?v=m-_ZnnGsnZ4
Types of Deafblindness	http://www.youtube.com/watch?v=BfRA4mKJwCE
Usher Syndrome	http://www.youtube.com/watch?v=8ewBngE9xc0
Deafblind Person's Communication Methods	http://www.youtube.com/watch?v=i-k7chINebM
Collaboration with SOCIEVEN	http://www.youtube.com/watch?v=SlInjo76H2KU .
Five Senses in Action	http://www.youtube.com/watch?v=no11UlpOAwS



Inclusion for a lifetime of opportunities

XV DEAFBLIND INTERNATIONAL WORLD CONFERENCE

Brazil – São Paulo – SP

September 27 – October 1 2011

Place

Bourbon Convention Bureau – Av. Ibirapuera, 2927 – São Paulo – SP

Local Planning Committee

President: Prof. Dr. Suzana M. Araújo –
Centro Universitário Luterano- Brazil
Mrs. Claudia Sofia Indalecio Pereira – Abrasc – Brazil
Prof. Dr. Elcie A. Fortes Salzano Masini –
Univ. de Presbiteriana Mackenzie – Brazil
Prof. Master Elenir Ferreira Porto Carillo – Adefav – Brazil
Prof. Master Marcia Maurillo Souza – Abrapassem – Brazil
Dr. Maria Aparecida Cormedi – Adefav – Brazil
Prof. Master Shirley Rodrigues Maia –
Grupo Brazil – Brazil
Prof. Master Stan Munroe – Deafblind International –
Canadian Deafblind Association – Canada
Prof. Master Vula Maria Ikonomidis – Ahimsa – Brazil

Scientific Committee

President: Prof. Dr. Isabel Amaral –
Instituto Politécnico de Setúbal – Portugal
Vice-President: Prof. Dr. Elcie A. Fortes Salzano Masini –
Mackenzie Univ – Brazil
Prof. Dr. Graciela Ferioli –
Perkins Internacional – Argentina
Prof. Gerard Roulstone – England
PhD Jude Nicholas –
Haukeland University Hospital – Norway
PhD Juliana A.F. Sallun –
Escola Paulista de Medicina – UNIFESP – Brazil
Prof. Penny Jane May-Kamu – England
Prof. Master Pilar Gomes Viñas- ONCE / Spain
Sr. Sam Boshielo – Africa
Prof Master Sonnia Margarita Villacrés –
Universidade de Guayaquil- Equador
Prof. Steve Perreault – Perkins International –
United States
Prof. Dr. Suzana M.M. Araújo –
Centro Universitário Luterano- Brazil

Promotion



Organisation



Institutional Support





Inclusion for a lifetime of opportunities

XV DEAFBLIND INTERNATIONAL WORLD CONFERENCE

Program

Day 26/09/2011 – (Monday)

Opening ceremony: 19:30

Day 27/09/2011 – (Tuesday)

Conference Opening: Deafblindness in Brazil
(09:00 – 11:00)

(ABRAPASCEM – ABRASC – ADEFAV – AHIMSA –
GRUPO BRASIL – PAHO)

Coffee Break: 11:00 – 11:30

Plenary Session: Inclusive Education (11:30 – 12:30)

Prof. Dr. Maria Bove (USA)

Response: Dr. Isabel Amaral (Portugal) –
Dr. Paulina Godoy (Chile)

Lunch: 12:30 – 14:00

Workshops: 14:00 -15:00

Poster sessions: 15:00 – 16:00

Workshops: 16:00 – 17:00

DbI General Assembly meeting: 17:00 – 18:00

Day 28/09/2011 – (Wednesday)

General Information: 08:30 – 08:45

Plenary Session: Pediatric Rehabilitation
(08:45 – 09:45)

Phd Jude Nicholas (Norway)

Response: Esp. Namita Jacob (India)

Break: 09:45- 10:00

Poster sessions: 10:00 – 11:00

Coffee Break: 11:00 – 11:30

Plenary session: Neurologic, Cortical Etiologies
(11:30 -12:30)

Prof. Dr. Juliana Sallum (Brazil)

Response: Ms. Ayola Cuesta (Colombia) –
Esp. Gabriela Rovezzi (Argentina)

Lunch: 12:30 – 14:00

Workshops: 14:00 – 15:00

Workshops: 15:00 – 16:00

Workshops: 16:00 – 17:00

DbI Network Meetings: 17:00 – 19:00

Day 29/09/2011 – (Thursday)

Tourist Day

Day 30/09/2011 – (Friday)

General Information: 08:30 – 08:45

Plenary session: Assistive Technology (08:45 – 09:45)

Prof. Dr. Al Cook (Canada)

Response: Ms. Rita Besrch (Brazil) – Mr. Anindya
Bhattacharyya Bapin (USA)

Break: 09:45 – 10:00

Poster Sessions: 10:00 – 11:00

Coffee Break: 11:00 – 11:30

Plenary session: Transition to adult life for young
adults who are deafblind
(11:30 – 12:30)

Dr. Steve Perreault (USA)

Response: Rocio Lopes (Costa Rica)

Parent panel: Dr. Susana Maria de Araoz (Brazil),
Mr. Joseph Shiroke (South Africa) and Gill Morbey
(UK)

Lunch: 12:30 – 14:00

Workshops: 14:00 – 15:00

Workshops: 15:00 – 16:00

Workshops: 16:00 – 17:00

Gala Dinner: 19:30

Day 01/10/2011 (Saturday)

Workshops: 10:00 – 11:00

Coffee Break: 11:00 – 11:45

Plenary session: UN Convention on the Rights of
People with Disabilities (11:45 – 12:45)

Mr. Lex Grandia (The World Federation of Deafblind)

Response: Dr. Ricardo Tadeu (Brazil) – Dr. Michael
Urtecho (Peru)

Closing ceremony: 12:45

More Information and Registrations www.dbi2011.com.br

THE OTHER SIDE OF THE COIN

gettyimages®



Living in two realities

An international conference on acquired deaf blindness, hosted by the Acquired Deafblindness Network in co-operation with Skåne Regional Council and Deafblind International.

Lund, Sweden

November 07-10, 2012

 **Habilitering & Hjälpmedel**
En del av Region Skåne

A D B N



Ges Roulstone reports on the activities of Deafblind Ireland



The board of Deafblind Ireland held its latest meeting on Saturday 18 June, 2011. Detailed discussion took place on the organisation's plans to develop a new training course on deafblindness, which will be the first to be offered in The Republic. It is hoped that a new course, to be offered on a modular basis via an Irish institute of higher learning, will commence in January 2012. The course

will be designed to cover elements including an overview of deafblindness, communication, orientation and mobility, learning / access to the environment, and functional assessment.

The course will be aimed at existing professionals who already work with deafblind children and adults. It will be offered as a certificated course of continuing professional development (CPD).

In addition the group



made plans for its next conference, to be held in Dublin on 19 November. The venue and conference title will be issued shortly.

Ges Roulstone
gesroulstone@yahoo.co.uk



**ANSPA the National Association
for Deafblind in France (Association
Nationale pour SourdsAveugles)**

is hosting the

**8th DbI European Conference
at the Lille Grand Palais
Lille, France**

27-31 August, 2013

The tentative title of the conference is **Identities and Changes**

Watch for future information on the DbI website
www.deafblindinternational.org
and in future editions of DbI Review

Acquired Deafblindness Network

Liz Duncan
Email: Liz.Duncan@sense.org.uk; info@adbn.org
Website: www.adbn.org

CHARGE Network

Andrea Scheele
University of Education Heidelberg
Schützenstraße 13
64625 Bensheim GERMANY
Tel: +496251939797
Email: andrea.scheele@gmx.de

Communication Network

Ton Visser
P.O. Box 7
5270 BA SINT-MICHIELSGESTEL
THE NETHERLANDS
Tel: +31 73 558 82 80
Email: ton.visser@kentalis.nl; viss7973@planet.nl

Congenital Deafblindness in Adults Network

Dominique Spriet
QUENEHEM BP 53 Rue du mont saint Eloi
CALONNE RICOUART 62470
FRANCE
Tel: +33 - 3 - 21 61 16 16
Email: sprieted@aftam.asso.fr

Employment Network

Seija Troyano
Nakskovinkatu 8 and 9
78200 Varkaus
FINLAND
Email: seija.troyano@pp.inet.fi

EDbN

Ricard Lopez Manzano
Joanot Martorell, street
08014 Barcelona
CATALONIA - SPAIN
Tel: +34-678-712-619
Fax: +34-678-782-600
Email: rlopez@sordoceguera.com
Website: www.edbn.org

Latin America Network

Sandra Polti
ARGENTINA
Email: sandrapolti@gmail.com

Outdoor Network

Joe Gibson
Sense Scotland
43 Middlesex Street
Kinning Park Glasgow G41 1EE
UNITED KINGDOM
Tel: 4+4 (141) 429-0294
Email: jgibson@sensescotland.org

Rubella Network

Nancy O'Donnell
Helen Keller National Center for Deaf-Blind Youths and Adults
141 Middle Neck Road
Sands Point, NY 11050
USA
Tel: + 516-944-8900 x326
Fax: +516-944-7302
Email: nancy.odonnell@hknc.org

Siblings Network

Sabine Kersten
Koningsbeemdstraat 3
Lommel, B 3920
BELGIUM
Tel: +32 476 612 879
Email: siblingsnetwork@gmx.net

Tactile Communication Working Group

Bernadette Van den Tillaart
15175 Prairie Road
South Solon OHIO 43153
USA
Tel: +1-740-426-6728
Fax: +1-740-426-6728
Email: bernadettevandentillaart@tiscalimail.nl

Usher Study Group

Tamsin Wengraf
Newplan House, 41 East Street
Epsom Surrey KT17 1BL
UNITED KINGDOM
Email: Tamsin.Wengraf@sense.org.uk

Employment

Challenges in the matter of influencing! Seija Troyano reports:

In the past few years I have often found myself comparing the work in the deafblind field in many ways to the field of politics. In both fields there are people making decisions, and influencing them is not always that easy, however much you wish to do. Of course you can always express your thoughts and point of views, but it does not mean that outcomes will happen the way you wish.

Democratic society makes decisions by voting and you have to accept the situation the results bring. Recently, for example, I watched the Eurovision song contest on TV and the final results. Next morning, people discussed in the media and on facebook whether the winner was the best singer with the best song or were the results because of the performers' country submitting the most votes.

Similarly, there are many different reasons to give towards a point of view in support of an issue. Influencing something towards a favourable decision requires a lot of effort and understanding how the ideas of many people are considered in the decision making process.

Politics is prevalent, even in our own field, although people do not like to use that 'P' word. For me, it is familiar word as I have spent many years in a place where politics is around us openly and officially.

There are so many options and points of view to consider when making a final decision, even with a small issue. You often wonder



why things must sometimes be so complicated. Where is the commonsense, the simple solutions, etc?

When I meet a friend who I got to know during my city council years, we tend to discuss the problems around us in our home town. We both agree influencing others is difficult, however important one thinks the issue is. Luckily, sometimes issues can be resolved easily. The key to solving problems often depends on decision makers sharing the same interest or point of view as you.

Now that I am nearing to the end of my Dbl Council post (2007-2011), many things are in my mind: some in a good order, some very confusing.

Through Dbl I have met many interesting people from different countries, learning so much from everyone. Influencing people in deafblind matters has been my main work during the Council (Board) meetings.

Thank you so much Dbl for that great opportunity you have offered me. Most of all, thank you members of Council (now the Board) for you have made me feel so very much "at home" in your presence. Hopefully I will see you all one more time in Brazil before the new Council (Board) members take office.

Kind regards,
Seija Troyano
seija.troyano@pp.inet.fi



CHARGE network

Andrea Scheele reports:

(UK), Martha Majors (USA), Andrea Scheele (Germany), Beatrix Zoppi (Argentina) and Alison McWilliams (Australia) during the European Dbl conference in Senigallia/Italy and are working out to fulfill the above mentioned intentions. Currently the Network is looking for new members, so, if anyone is interested, please contact us to advise what your expectations for the network might be.

We are planning a CHARGE Network meeting during the Dbl World Conference in Sao Paulo, Brazil. We are looking that you to share in our meeting on Wednesday, September 28, 2011, 1700-1900 hours.

In addition to providing an opportunity to share knowledge and expertise amongst those professionals with experience in the field, the Dbl CHARGE Network also serves as a contact point for those professionals who are new

to working to support individuals with CHARGE. The Dbl CHARGE Network does not intend to replicate existing CHARGE family support group websites.

How do people become a member of the Dbl CHARGE Network?

Provide an email address for the group email then participate in upcoming network meetings.

If you are: interested in the group, thinking about joining and contributing to our network meeting during the Brazil Conference, or if you have no chance to join the meeting but you are interested in the results from that meeting or other CHARGE Network meetings, please contact us via email.

Andrea Scheele
CHARGE Network
andrea.scheele@gmx.de

The CHARGE Network is an inclusive, interdisciplinary and worldwide Dbl network of professionals in the field of CHARGE syndrome. Its intention is to provide an opportunity to share experiences, highlight resources (e.g. literature references, website signposts/links), organize a discussion forum (with current questions/issues addressed in the form of a 'topic of the month' to structure the exchange), and support research through naming important questions and circulating research information/requests, etc. We set up a new task group consisting of Gail Deuce

Outdoor Network

Joe Gibson introduces Dbl's newest network

Welcome to the new Dbl "Outdoor Network"! This network is for all people who enjoy or use the outdoor environment. It is open to people whose deafblindness is either acquired or congenital, family members and support staff. We hope this network will encourage deafblind people and the people who support them to use and enjoy the outdoor environment by:

- Promoting the use of the outdoors with and for people who are deafblind for leisure,

educational and therapeutic purposes.

- Developing an understanding of some of the theories relating to the beneficial use of the outdoor environment and how these might apply to people who are deafblind.
- Sharing practice of, and opportunities for, using the outdoors with people who are deafblind.
- Sharing different cultural ways of using and viewing the outdoor environment.



If you would like to be a part of this network, have an outdoor event you wish to publicise or just want more information please contact Joe Gibson.

Joe Gibson
Outdoor Network
jgibson@sensescotland.org.uk

ADBN

Acquired Deafblindness Network; Liz Duncan reports:

Well, after a very successful Conference in Aalborg, Denmark last October, the ADBN co-ordinating group are now deep into the planning of the next Conference, which will be in Lund, Sweden in 2012.

We received lots of really good and useful feedback from the conference in Denmark. We have looked closely at what participants said about the content of the plenary and workshop sessions and are using these comments to help identify themes, speakers and new ideas for our next conference in Lund Sweden.

The ADBN co-ordinating group has undergone several changes over the last year. Ges Roulstone from the UK stood down in June 2010 after leading the network very pro-actively for a number of

years. Ges was replaced by Bernard De Vries from the Netherlands; who successfully led us throughout the final planning stages of the Conference in Aalborg and chaired what one delegate described as 'a stellar conference'. Bernard has now retired from his role at Visio and from ADBN (for the 2nd time!). The Co-ordinating group would like to thank him for his contribution to the work of ADBN. His quiet wisdom, passion, commitment, knowledge and wonderful sense of humour will be impossible to replace. I would like to thank him for his support and encouragement to me personally throughout our time together with ADBN.

These are difficult times, with many organisations that support Deafblind people facing massive changes as a result of changes to



social policy. This makes it even more important that we network with each other and use not just the experiences and knowledge from our own countries, but also those of our colleagues elsewhere, so I would encourage you all to use the network, make contact with each other, support and learn from each other and we hope to see you all in Malmo in 2012.

**Liz Duncan, Chair, ADBN
Co-ordinating group
Liz.Duncan@sense.org.uk**

Communications Network Ton Visser reports:

The members of the Dbl Communications Network met in Groningen, The Netherlands, March 8 -9, 2011. This time our meeting was combined with a seminar on Reliability and Dialogicality. This was organised in cooperation with the University of Groningen. Two of the plenary speakers from the 2010 Paris Conference, Professors Ivana Markova and Per Linell, were invited to give a guest lecture on this theme on March 08. The following day, March 09, two graduated students, Franck Berteau and Heather Colson-Osborne, from the MSc in Educational Sciences 'Communication and Congenital Deafblindness' Program, presented their Masters Thesis.

Invited this time to the

meeting were the former and current enrolled students from the Master on Communication and Congenital Deafblindness Program. The members of the Dbl Communications Network organised this meeting in an attempt to clarify the concept of 'Dialogicality' in a more scientific way. We have felt for a long time the need to find well defined and accepted research methodologies to give our work based on the concept of 'Dialogicality' a more scientific grounding. At the end of these very successful days, each of us had the feeling of a better understanding about the possibilities of this type of research.

During this session, we repeated the way of working that we did at the beginning days with our group. In that time we frequently

organised a seminar to try to develop our knowledge; followed by a conference to share and to develop this knowledge further. In October, 2011 we will meet each other again to study further on this topic. Our intention is of course to organise a conference on this topic in the near future. If you have any suggestions or questions, please feel free to contact us. If you send your email to me, I will determine who is best in our group to respond to your email.

To those who are going to the Dbl World Conference in Brazil in September, on behalf of all the members of the Dbl Communications Network, have an inspiring and wonderful conference!

Ton Visser

The Siblings Network Sabine Kersten reports:

Sometimes siblings like being with their brother or sister and enjoy each other's company. At other times they really don't want to do anything with them. It is normal to sometimes feel caring and protective; at other times to feel irritated with your brother or sister. It is important that siblings (and parents) know that having these mixed feelings is normal and that they need to learn how to deal with all these positive and negative feelings.

Adult siblings also need access to information. As many of them juggle multiple responsibilities, they may feel isolated and may need support in their sibling role.

Adult siblings may experience difficult feelings like resentment about the impact of the disability on their childhood and their life choices. They can have feelings of sadness and loss.

Siblings may have to deal with a number of caring issues. What will happen with regard to future care of their disabled sibling? How will they juggle their responsibilities managing their own life, their personal work and family life, while simultaneously taking care of their sibling and possibly aging parents. All complicates trying to achieve this one goal: to make sure that their brother or sister has a good quality of life.

The relationship between the adult sibling and their parents may also be affected, as parents may experience difficulties in dealing with the whole situation. Siblings may also experience feelings of loss of their relationship with their brother or sister if he/she went to live in residential care.

This does not mean it is all negative. Many siblings tell that they experience unexpected opportunities from these responsibilities as well. These

'opportunities' may include developing new skills and knowledge in areas such as parenting, psychology, communication. Their level of empathy toward others may be enhanced, as well as developing more competence in dealing with practical tasks.

These are all thought and concerns from people in the Siblings Network. The Network is always striving for more information and support for all siblings dealing with people with deafblindness.

For more information please contact the network.

**With kind regards,
Sabine Kersten
siblingsnetwork@gmx.net**



Rubella Network

Nancy O'Donnell reports

These days, it is rare to find an entire book dedicated to rubella. "Dangerous

Pregnancies: Mothers, Disabilities and Abortion in Modern America" by Leslie Reagan, Ph.D., is a recently published book about the impact of rubella from a historical perspective.

I met Dr. Reagan in 2008, when she visited the Helen Keller National Center library as part of her research for this book. She was looking for information about the effects of rubella on families, politics, and society as a whole, and on mothers in particular. Her book brings us back to the 1960's, the period of the rubella

pandemic. It walks us through its impact on society, health care, laws, educational policies and human rights, up to the current day. It is a must read. (University of California Press, ISBN 978-0-520-25903-4).

Stan Munroe reports that the Canadian Deafblind Association (CDBA) will be conducting a follow up survey on adults with Congenital Rubella Syndrome (CRS). This will be an update to the 1999 Canadian survey on the "Late Manifestations of Congenital Rubella Syndrome". This new project will include distributing a new questionnaire to families and facilities to learn more about

the ongoing impact of these late emerging medical and behavioural conditions believed related to Congenital Rubella Syndrome.

**Nancy O'Donnell
Director of Information, Research
and Professional Development
Helen Keller National Center for
Deaf-Blind Youths and Adults
141 Middle Neck Road
Sands Point, NY 11050
516-944-8900 ext 326
nancy.odonnell@hknc.org
www.hknc.org**



Tactile Communication Network

Bernadette van den Tillaart reports:

Members of the Tactile Communication Network are preparing for a Pre-Conference preceding the XV International Conference in Sao Paulo, Brasil. At the Tactile Communications Network session during the Dbl European Conference in Senigallia, Italy in 2009, attendees had a preview of the movie "Landscape of Touch", along with guided simulation exercises, followed by a lively discussion. The many participants at the end of the meeting were asked if we would be willing to organize a future multi-day event to share what we have developed over the last several years.

This Pre-Conference in Brazil is the result of this discussion. During this event in Sao Paulo, September 25-26, we hope to reach out to the international community in the deafblind field. We appreciate the helpful and friendly support from the organizers of the Dbl International Conference in Brazil to assist us with hosting this pre-conference. We are also grateful for the generosity of those Brazilian organizations that offered to cover the costs and registration fees for this event. Interested participants that would like to attend can do this for free.

The overall theme of this pre-conference is "Touch as Central to Learning, Communication and Access for Persons with Deafblindness". The event will

focus on enhancing awareness of touch in seeing-hearing people so that they can become skillful and adequate partners for persons who are deafblind. The sessions will include presentations on theoretical frameworks, practical ideas and applications in professional practice regarding tactile communication.

All persons communicate for the purposes of understanding each other, establishing relationships, obtaining information, working and living together and just enjoying the opportunity to communicate with one another. One of the main consequences of deafblindness is an enhanced ability to use the tactile sense. It is often not possible to communicate effectively with a person who is deafblind using only typical auditory and visually modalities. Communication often needs to be supported by the tactile mode in order for it to be meaningful and truly reciprocal for the person with deafblindness and their communication partner.

Hearing and sighted persons are often not very aware of their tactile sense. To become competent partners of people who are deafblind, they need to understand what it means to rely on their sense of touch, as people who are deafblind must do. To experience the complexity and richness of the tactile world, they need to develop skills



for themselves in using tactile communication.

Therefore, among the topics of the preconference are the tactile sense, tactile awareness and experience, tactile comfort and culture, tactile exploration, establishment and continuation of meaningful tactile contact and communication, tactile traces and narrative, and tactile access to language and environment.

The participants will view the movie 'Landscape of Touch', participate in exercises, presentations and discussions and get access to staff training suggestions and further resources.

Needless to say that we look forward exchanging images, knowledge, ideas and stories with the participants! You are invited to attend this pre-conference. For more information refer to the XV Dbl Conference website (www.dbi2011.com.br) or the Dbl website (www.deafblindinternational.org). For pre-conference registration contact the Brazil organizing committee by email: cisinando.lima@ahimsa.org.br

We look forward seeing you!

Bernadette van den Tillaart
Tactile Communication Network
Email: bernadettevandentillaart@tiscalimail.nl

“Communication often needs to be supported by the tactile mode in order for it to be meaningful and truly reciprocal for the person with deafblindness and their communication partner.”

European Deafblind Network (EDbN)

Lucy Drescher reports additional European countries receiving recognition of deafblindness status

In 2004, the European Deafblind Network (EDbN) was successful in getting 'Written Declaration - 1/2004', recognizing deafblindness as a unique disability, adopted by the European Parliament. This was the culmination of a campaign by deafblind people, family members and professionals across Europe, persuading over half of the Members of the European Parliament to sign up to the declaration. A 'Written Declaration' is not a piece of legislation; it does not force anyone to do anything. However, it is a European document which can be used to make a case for deafblind people receiving the rights they are entitled to.

A 2005 EDbN report on this initiative indicated that only four of the twenty five Member States had received recognition status for deafblindness. Those countries were Denmark, France, Sweden and the UK.

In the years since, people in a number of countries have been using the 'Written Declaration', along with the UN Convention of the Rights of Disabled People and other national documents to try to get recognition of deafblindness status for their country. Now, out of the twenty seven Member States, eight have received the recognition of deafblindness status. This is great news as the number has now doubled. In addition to the countries

previously mentioned, Romania (which already had recognition status and is now a European Member State), Italy, Spain and Austria have recently received the recognition of deafblindness status. Congratulations to Italy, Spain and Austria!

If you are trying to get recognition of deafblindness in your country, whether you are in the European Union or elsewhere, do let us know so that we can offer you advice and support.

Lucy Drescher
Sense Campaigns and
Public Policy Officer
Lucy.Drescher@sense.org.uk

Debbie Karazinski proposes developing a new Dbl Network called

The Australasian and South East Asian Deafblind Network

Senses Foundation, in Western Australia, is keen to form an Australasian and South East Asian Deafblind Network in a similar manner to the other world networks – the European Deafblind Network and the Latin American Network. The countries in such a network would be all those within the region and would likely include Australia, Myanmar (Burma), Cambodia, Cook Island, Fiji, French Polynesia, Indonesia, Kiribati, Malaysia, Nauru, New Caledonia, New Zealand, Niue, Pitcairn Island, Papua New Guinea, Philippines, Singapore, Solomon Islands, Tokelau, Thailand, Tonga, Tuvalu, Vanuatu, Wallis Futuna and Western Samoa.

At the 2010 Australian Deafblind Conference in Victoria, Australia and more recently at the Deafblind

Communication Training with Paul Hart and Megan Mann from Sense Scotland and Sense UK in Western Australia, also in 2010, there was discussion about the need to encourage networking between Australian organisations working with people who are deafblind and also to encourage that networking within the Australian and South East Asian region. There are not many such agencies so it would only be a small group in the beginning. However these agencies are all providing interesting programs which are well worth sharing.

As is the case with other regional networks, this proposed Australasian and South East Asian Deafblind Network could stimulate opportunities for cooperation and collaboration in training, research, policy development and

best practice, as well as promote awareness of deafblindness.

It is proposed that interested organisations establish a small steering group to form this Network. In Australia, the Senses Foundation and the Royal Institute for Deaf and Blind Children have both indicated their interest as has the Royal New Zealand Foundation of the Blind in New Zealand. According to Dbl rules, we only need one other country to want to be involved in order to form a network.

If you are interested in hearing more or being involved in the development of an Australasian and South East Asian Deafblind Network, please contact Debbie Karasinski, Chief Executive Officer, Senses Foundation by email dkarasinski@senses.asn.au

Helen Keller International Award



Playboy Braille film wins 9th Helen Keller International Award

A short film in which a woman reads aloud extracts from a Braille edition of Playboy magazine, has won the 9th Helen Keller International Award. Created by Caroline Douglas, an MFA Graduate from Glasgow School of Art who lives in Edinburgh, the 5 minute film features a woman reading an article from the June 1996 edition of Playboy, in Braille. The judges felt the piece 'worked on a number of levels and had the greatest impact'.

The judges, Francis McKee (Director of CCA), John Shankie (Artist), and Monica Callaghan (Head of Education, Hunterian Museum and Art Gallery) spent some time choosing the winner and runners up, in an exhibition which they felt, set the bar high in terms of quality, diversity of approach and aesthetics.



Caroline Douglas, winner of 9th Helen Keller International Award

9th Helen Keller International Award winning works:

Winner:

Playboy Entertainment for Men, Braille Edition June 1996 (film) – by Caroline Douglas from Scotland

Highly commended:

Whistling Man (film) – by Yael Schmidt from Israel

Highly commended:

Colours (Digital Image) – by David Frame, Scotland

Highly commended:

Guidedog Amber (Painting) – by Marianne Angela Fennymore from England



Braille edition of Playboy magazine

Exhibition curator Isobel MacRae, from the Sense Scotland Arts Team, is enthusiastic about this year's exhibition:

"I think visitors to the exhibition will find a fantastic variety of artworks to experience and explore, across a wide range of mediums. From large-scale installations featuring sound and water, to intimate tactile paintings and sculptures, it's a great chance to see these emotive and challenging works, which explore the senses."

Exhibition Dates/Times: 9th – 26th May 2011 –

Mon – Sat 10am – 6pm

Venue: Glasgow Caledonian University, CPD Centre, Cowcaddens Road, Glasgow G4 0BA

Run by charity Sense Scotland's Arts team, the exhibition features work which challenges perceptions of deafblindness and sensory impairment. Hosted by Glasgow Caledonian University the winner was announced at an award ceremony by the charity's Patron, The Duchess of Sutherland.

To contact the Sense Scotland Arts team

Email:

arts@sensescotland.org.uk

Phone: +44 (0)141 429 0294

Fax: +44 (0)141 429 0295

Text: +44 (0)141 418 7170

Web: www.sensescotland.org.uk/helenkeller

Media enquiries to Graeme Thomson: Tel: 0141 418 7178
Mob: 07717 133538
Email: gthomson@sensescotland.org.uk

Helen Keller International Award partners:

Editor's notes:

- Sense Scotland works with people who have communication support needs because of deafblindness, sensory impairment, learning and physical disabilities.
- Sense Scotland's arts team have been supporting activities, tailored to individual interests and abilities for over 10 years. Across Scotland the arts, music, drama and outdoors, practitioners are highly skilled in encouraging creative approaches with disabled people, to enjoy sessions, performances, exhibitions and outdoor pursuits.

Prizes for Helen Keller International Award:

- the Helen Keller International Award winner receives a specially designed trophy and cheque for £1500
- three Highly Commended Runners Up receive the E.D.G.D. Fairfull-Smith, the G.W. Fairfull-Smith and the Neil Fairfull-Smith Awards plus a £200 cheque

Gillian Morbey appointed as Sense UK Chief Executive



Gillian Morbey, former CEO of Sense Scotland, was appointed this past spring as CEO of Sense UK, after serving as interim CEO since October, 2010.

With over 25 years' experience in the deafblindness sector, Gill is recognised both in the UK and internationally for her contribution to supporting deafblind people. Gill serves on the Management Committee of Deafblind International.

One of the founding members of Sense Scotland (1977), Gill watched the organisation grow from a small parents' mutual support group to what is now a significant charity working with over 500 deafblind children and adults throughout Scotland. Gillian is the mother of two children, one of whom is deafblind due to congenital rubella syndrome.

Gillian is a Registered General Nurse with an honors degree in psychology. In 1984/85 Gillian, with Dr

Stuart Aitken of Edinburgh University, completed the first research study into the numbers of deafblind people in Scotland. This was published under the title *Look, I'm here*. Since then she has addressed many conferences and contributed articles to a number of journals and other publications on the subject of deafblindness and family issues.

Gillian was awarded the O.B.E. in 1995 in recognition for her work in the disability field in Scotland.

Aubrey Webson appointed director of Perkins International

As Director of Perkins International, Dr. W. Aubrey Webson oversees the global mission of Perkins School for the Blind by working with hundreds of partners in 65 countries. Since coming to Perkins in 1992, Webson has led initiatives to grow services in Africa and the Caribbean; helped shape educational services for children who are deafblind and those with multiple disabilities; supported government and service workers in policy development; and introduced and implemented the Institutional Development Program (IDP), a capacity building project for organizations of the blind in Africa and the Caribbean. IDP is the organizing body for the quadrennial Africa Forum conference. The fifth Africa Forum is being held in Accra, Ghana, July 3-8, 2011.

Webson formerly worked with SightSavers International, Helen Keller International, and was Executive Director of the Caribbean Council for the Blind. He holds a PhD. in Management from Case Western Reserve University (Cleveland, OH) and has published in the field, including his 1998 book, *Empowerment of the Blind*.

As a native of the Caribbean island of Antigua Barbuda and as person who is blind, Webson understands the developing world. Furthermore, knows first-hand the importance of family support and access to education. He believes that all children have the capacity to learn, all families have love to share, and all people deserve the chance to develop to their potential. That belief coincides with the Perkins International mission of improving the



Aubrey Webson

quality of life for children who are deafblind or blind with multiple disabilities throughout the world. Webson and his team of Perkins International regional coordinators work with policy makers, families, educators, and students to expand services; to bring resources and opportunities where none exist; and to join the world community in the social network of creating possibilities for all.

“As a native of the Caribbean island of Antigua Barbuda and as person who is blind, Webson understands the developing world.”

Ahimsa (Brazil) celebrates 20 years

We completed 20 years with many accomplishments and successes. It was a long and difficult journey, but we have much to be thankful for. First of all, we thank God for blessing us, our students, families, trainees, volunteers and everyone who has helped and believed in our dream.

Our most sincere thanks!
Ahimsa



Historical data...

Foundation – 1991



3 students

2001



99 students

2011



240 students

Professionals trained

In partnership with the Ministry for Education (MEC), AHIMSA has trained professionals in over 660 cities in all 27 states of Brazil on such topics as:

Special Educational Services
3,500 professionals

Training local leaders in Deafblindness and Multiple Disabilities (years 2006, 2007 and 2008)
600 professionals

Diversity Training Programs
3.500 professionals

In partnership with the State Secretary of Education of São Paulo AHIMSA has put on such courses as:

Video Conference: Themes on Deafblindness and Multiple Disabilities :
3,900 professional participants

Intervenor Training Course
32 professionals trained in 30 different cities

Deafblindness and Multiple Disabilities Course
320 professionals trained from the Department of Education in São Paulo State

In partnership with the City Secretary of Education of São Paulo:

Deafblindness with Multiple Disabilities and Intervenor Courses (2009 and 2010)
650 professionals trained in public schools of the city of São Paulo

“The best and most beautiful things in the world cannot be seen or touched, but are felt with the heart”

Helen Keller

Children's services

In partnership with families we offer guidance and support for children up to age 6 years to help improve their quality of life



Functional I

Program Functional I offers specialized services for children ages 6 to 14 years with deafblindness/multiple sensory disabilities



Functional II

Program Functional II offers specialized services for young adults (ages 14-21) and adults with deafblindness/ multiple sensory disabilities.



Functional II

This program also includes the Phoenix Program designed especially for children and young adults who have never attended school before. We also offer the Home Visit Supported Families Program for those who cannot come to our facilities.



Workshops

We offer such workshops as:

- Stationary • Arts and Crafts • Cold dough modeling • Mosaic • Sewing • Origami • Baking • Computer Science



Rehabilitation for people who are Blind, Deafblind and Multiple Disabled

In the rehabilitation program we offer several techniques for communication including Sign Language, Braille and Orientation and Mobility.



AHIMSA – Educational Association for Multiple impairment
 Address: Rua Baltazar Lisboa, nº 212
 Vila Mariana - São Paulo – SP
 CEP: 04110-060

Contact:
 Cisinando Carlos da Costa Lima
 Tel: (11) 5579-5438 Cel: (11) 9596-7330
 E-mail: cisinando.lima@ahimsa.org.br
 Website: www.ahimsa.org.br

An Exceptional Fellow

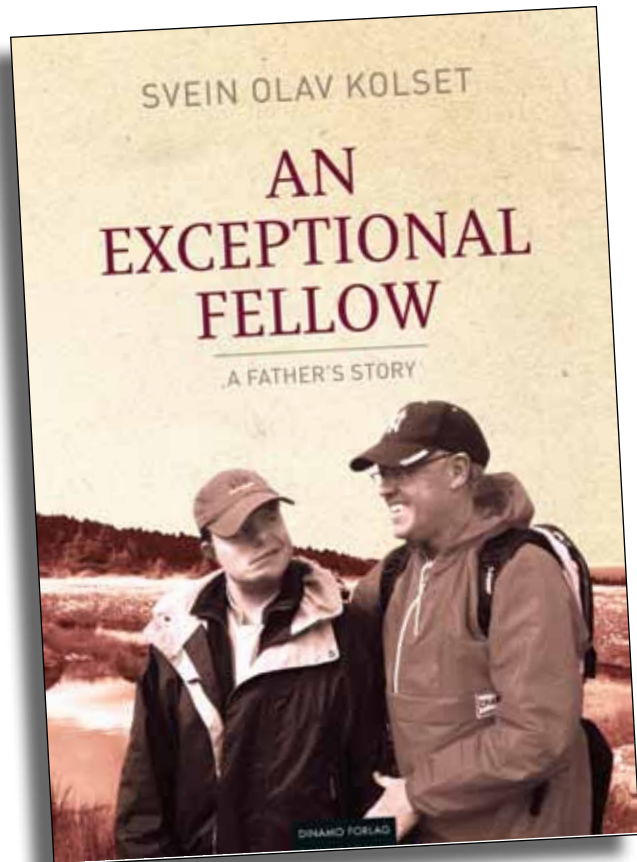
An Exceptional Fellow is the unsentimental and powerful story of a child with multiple disabilities and his family. The boy is Torgeir, now 35 years of age. The father, Svein Olav, relates the shock his wife experienced one day in May 1975 when Torgeir came into the world. We hear the story of a young student couples' struggles with everyday life and about the significance of friends and family in the social circle surrounding Torgeir.

Torgeir is a tough guy. He is another kind of Viking. Against all odds he has fought for and achieved a life of dignity. He experiences mastery and meaning on his own terms. How is that possible with serious sensory debilitation and other physical impairments?

His father tells us how, and about the journey to an accurate diagnosis - CHARGE.

An appeal to our sense of collective social responsibility for the most vulnerable among us runs like a red

“An appeal to our sense of collective social responsibility for the most vulnerable among us runs like a red thread throughout the book”



thread throughout the book. Is there any point in dedicating the greater portion of one's life to "damaged goods"?

The answer - a resounding YES - resonates profoundly through the declaration of love that this book represents.

"I write to illustrate a life lived and fought for outside of the spotlight. Life with Torgeir has been a dramatic and difference journey. I write because he cannot tell his story personally. I write to lift him and his peers out of oblivion...!"

Svein Olav Kolset

The former Prime Minister of Norway, Mr. Kaare Willoch, has written the book's foreword. He says: *"This book is first and foremost a gripping documentation of the human capacity for caring and warmth, and about despair that is converted into creative action."*

For information on obtaining a copy of this book, please contact Dinamo Forlag at post@dinamoforlag.no

Dangerous pregnancies

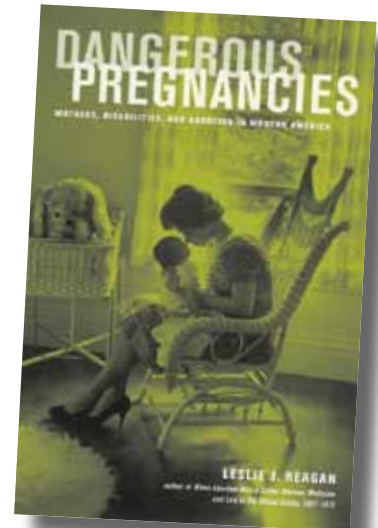
Mothers, Disabilities, and Abortion in Modern America

Leslie J. Reagan (Author)

Dangerous Pregnancies tells the largely forgotten story of the German measles epidemic of the early 1960s and how it created national anxiety about dying, disabled, and “dangerous” babies. This epidemic would ultimately transform abortion politics, produce new science, and help build two of the most enduring social movements of the late twentieth century--the reproductive rights and the disability rights movements. At most a minor rash and fever for women, German measles (also known as rubella), if contracted during pregnancy, could result in miscarriages, infant deaths, and serious birth defects in the newborn. Award-winning writer

Leslie J. Reagan chronicles for the first time the discoveries and dilemmas of this disease in a book full of intimate stories--including riveting courtroom testimony, secret investigations of women and doctors for abortion, and startling media portraits of children with disabilities. In exploring a disease that changed America, Dangerous Pregnancies powerfully illuminates social movements that still shape individual lives, pregnancy, medicine, law, and politics.

Leslie J. Reagan is Associate Professor of History, with affiliations in gender and women’s studies, law, media and cinema studies, and medicine, at the University of Illinois, Urbana-Champaign. She is the author



of *When Abortion Was a Crime: Women, Medicine, and Law in the United States 1867-1973* (UC Press) and coeditor of *Medicine’s Moving Pictures: Medicine, Health, and Bodies in American Film and Television*.

Available worldwide
Hardcover, 392 pages
ISBN: 9780520259034
July 2010

Screen Braille Communicator

Communication Device for Deafblind people

Lagarde communications announces a new communication device available for deafblind people, called the screen Braille communicator. This device makes it possible for deafblind people to communicate with people who can see.

The communication works interactively. The visual person types a text into the device; the deafblind

person reads the text (in Braille with 8 Braille cells) and then responds via the Braille keys. This answer will be shown in the appropriate language on a LCD display.

This can be seen in the three pictures below: 1 typing the text, 2 reading the text in Braille and, 3 typing text in Braille. In this way a deafblind person can communicate with other people without any physical contact.

The screen Braille communicator is very easy to use and simple to handle. Also people not used to computers can easily use this device. The device is small and light and uses a rechargeable battery, allowing it to be carried easily.

For further information about specifications and price, contact Chris Lagarde by email (clagarde@xs4all.nl) or online www.lagardecommunication.com



1) Seeing person types the text



2) Db person reads the text in Braille



3) Db person types text in Braille

DbI Management Committee travels to Singapore



Management Committee meets with Koh Poh Kwang at the Lighthouse School in Singapore

Asian hospitality was at its highest during ManCom's visit to the spectacular country of Singapore during the first week of April, 2011.

Committee members were treated to outstanding accommodations, food and conference meeting room services at the award winning exquisite Furama Riverfront Hotel.

Topping off the total experience in Singapore was the hospitality from our host and Board Member Koh Poh Kwang, along with his gracious wife Yang Lan Kwai.

Mr Koh organized dinners, tours and shuttle services to and from the airport. He was host extraordinaire!

The Management Committee spent several successful days in meetings to progress the work of Deafblind International. More information on this is provided in the Secretary's report.

Following our meetings, we made two visits to schools. The first visit was to Ahmad Ibrahim Secondary School which provides specialized services for the visually impaired. This visit included an informative session with staff members, some of whom were visually impaired, speaking about services for disabled people in Singapore. The second visit was to the Lighthouse School, formerly called the Singapore School for the Visually Handicapped where Mr Koh is the Principal. We had

a wonderful tour through this facility situated in a pleasant environment, encompassed by gardens and exotic vegetation.

Our visit through the school demonstrated the school's philosophy "that our pupils with different disabilities are able to receive education/training to develop his/her potential to the fullest through realistic experiences and life skills".

We had an opportunity to interact with students with various disabilities, including deafblindness and to meet some of the excellent staff.

We sincerely thank Mr and Mrs Koh for a truly memorable experience and for being such impeccable hosts.

Deafblindness and mental distress

Sarah Miller (née Bodsworth) and Isabel Clare

Sarah's story

My mother was born with partial hearing. During my adolescence, she attended a routine optician's appointment and returned with a diagnosis of Usher Syndrome Type II, meaning that she would progressively also lose her eyesight. For my mother, it was a relief, after years of knowing something was not right. However, she was very fearful of the challenges ahead. The impact of her deafblindness eventually led to mental distress. She sought professional support, but found none.

My mother's experiences had a profound effect upon me. I found that much was known about mental distress from the experiences of people with deafblindness, but that knowledge was fragmentary and largely anecdotal. Very limited systematic information was available. At University, I used my undergraduate research project as an opportunity to explore the area of deafblindness and mental distress^{1,2}.

The research

We devised a survey, using the General Health Questionnaire³ (retitled the 'How You Feel' Questionnaire), an established self-report

measure of symptoms of mental distress, with some extra items and space for people to tell us about their own experiences. Deafblind UK, one of the leading UK organisations for people with deafblindness, translated the survey into each of their member's preferred format before sending them out. As in other research with people with communication difficulties, the response rate was low (20%), but the respondents were representative, at least in terms of age and gender, of the membership of Deafblind UK. We received 539 anonymised responses, from England, Wales, and Scotland, that could be used in part or in full. More than half were from older people, aged at least 65 years.

Our findings

1. Mental distress affects many people with deafblindness

We found that almost half the men and women in our sample (45.8% of 439 respondents) reported high levels of anxiety, depression, physical symptoms and/or social impairment. Using an established definition³, these men and women were experiencing 'mental distress', requiring more detailed assessment and, if necessary, treatment, by a health care practitioner.

2. Deafblindness is a risk factor for mental distress

Our findings showed that mental distress is three times more common among people with deafblindness than among the general adult population. It is more than twice as common as among other older people.

Our respondents reported experiences of social isolation, a loss of independence, and the impact of other people's negative attitudes. These are all likely to be relevant to their mental distress:

'Because I have a lot of problems and all are getting worse and I am stuck here alone all daytime – I cannot guarantee I will be here tomorrow. I think about dying constantly'

'I feel isolated... and sometimes feel like a social outcast'

'(I am) perceived as someone who is unable to speak for themselves, which is not the case'

3. Access to support from primary care is limited

According to our respondents, only one in three (177 responses) was receiving support, for mental distress – or another health care issue – from primary healthcare practitioners, such as family doctors (General Practitioners) or nurses.



Sarah Miller
(née Bodsworth)



Isabel Clare

“There should be much more help and support for those people recently diagnosed... I would not wish my experience on any one”

Only one in twenty was in contact with a mental health specialist such as counsellor, psychologist, or psychiatrist. In fact, formal (paid) support of any kind was rather limited, in both its range and its frequency. Overwhelmingly, support was provided informally by family members and/or friends.

4. Limited support is available around diagnosis

Fewer than six in ten respondents (527 responses) reported that they had received any kind of formal psychological or practical support at the time their deafblindness was diagnosed. Of the rest, a substantial majority reported that they would have welcomed such support, particularly from ‘someone in the same shoes’.

‘(T)here should be much more help and support for those people recently diagnosed...I would not wish my experience on any one’

What next?

At present, there are about 335,000 adults with deafblindness in the UK⁴. The findings of our small survey suggest that more than 153,000 of them experience mental distress and would benefit from further assessment of their symptoms. This is shocking. As far as we can ascertain,

the number of people with deafblindness worldwide is unknown. However, the results of our survey could prove to be useful for service providers in other countries. Complementing and extending existing UK guidance, the findings of our small survey lead to four main recommendations:

1.Improvements in primary care provision

Primary care providers, such as family doctors and health community-based nurses, should ask patients with a diagnosis of deafblindness, and indeed anyone with a dual sensory impairment, about symptoms of mental distress. In the UK’s National Health Service, family doctors, in particular, have a crucial role, both directly, and through referrals to specialist mental health practitioners, such as counsellors, psychologists, and psychiatrists, in the assessment and treatment of mental distress. However, treatment for mental distress need not always involve specifically psychological interventions or medication. Practical support that increases opportunities for social engagement and physical activity (such as the provision of a specialist one-to-one support worker) can also have a powerful positive impact on mental well-being.

2.Improvements in secondary care

Specialist outpatient services (audiology, ophthalmology) should be aware of the psychological impact of a diagnosis of deafblindness and routinely screen for, and and ask questions about, mental distress. There is considerable scope for involving organisations representing people with deafblindness and their carers, such as Deafblind UK and Sense in the UK, in the support of men and women whose dual sensory impairments have just been diagnosed.

3. Training for social care and other providers in contact with older people

Since deafblindness is much more likely to affect older than younger people, support workers in health and/or social care services for older people should have training in identifying the signs of mental distress and ‘good practice’ in supporting access to primary and other health care services, as well as an understanding of the guidance to local authorities⁵.

4.Greater awareness among people with deafblindness and their carers

People with deafblindness themselves, and the families and friends who provide so much of their care,

“Practical support that increases opportunities for social engagement and physical activity (such as the provision of a specialist one-to-one support worker) can also have a powerful positive impact on mental well-being”

should have user-friendly information, in properly accessible formats, about the increased risk of mental distress, and when and how to access assessment and support.

Over the next few decades, huge increases are expected in the number of people with deafblindness worldwide. In the UK alone, it is estimated that, by the year 2030, there will be

570,000 deafblind men and women, an increase of 60%⁴. While there is evidence of progress, greater awareness of the condition and its impact, and improvements in health care provision, are needed urgently. Otherwise, we face a future in which the experiences of Sarah’s mother will be all too common.

Sarah Miller (née Bodsworth) and Isabel Clare

Notes

- 1 This article is based on a paper by S.M. Bodsworth, I.C.H. Clare, S.K. Simblett, and DeafblindUK (2011) Deafblindness and Mental Health: Psychological distress and unmet need among adults with dual sensory impairment, *British Journal of Visual Impairment*, 29 (1), 6-26. We are grateful to the journal’s Editors for permission to write the article. If you would like to view or purchase a copy of the full paper, please visit: www.bjvi.sagepub.com. This article is a slightly revised version of ‘Deafblindness and mental distress’, which first appeared in *Talking Sense*, Spring 2011, 36-38. *Talking Sense* is the magazine of Sense, one of the leading UK charitable organisations for people with deafblindness and associated disabilities. We are grateful to the Editor for permission to reprint the material.
- 2 We are also grateful to Deafblind UK and the Department of Psychiatry, University of Cambridge, for support with the survey, and to Annette Bodsworth. Isabel Clare and Sara Simblett are funded by the NIHR CLAHRC for Cambridgeshire & Peterborough.
- 3 Goldberg, D.P. and Williams, P. (1988). *A User’s Guide to the General Health Questionnaire*. UK: Basingstoke Press Ltd. We used the established conservative criterion of ‘caseness’ (a score of 4 or more out of 12) to define ‘mental distress’.
- 4 Sense (2010). *A Sense of Urgency*. www.sense.org.uk/Resources/Sense/Publications/Documents/SenseofUrgency.pdf
- 5 Department of Health (2009) *Social Care for Deafblind Children and Adults*. Local Authority Circular 6 (LAC (DH) (2009)6). London: Department of Health.

Berit Øie completes the 2010 New York City Marathon

The following commentary written by Norwegian deafblind woman Berit R. Øie, gives an insight into her experiences related to running the New York City Marathon, November 2010. This article appeared in the first edition of the publication (News on Acquired Deafblindness) of The Danish Resource Centre on Disability and Social Psychiatry (<http://www.dbcent.dk/cgi-bin/vcfdbb/uploads/media/pdfs/NYT.pdf>).

“Finally came the day when I could get my running legs on the streets and bridges of New York. It was November 07, 2010, the day of my first ever marathon; I was very excited. It was sunny, four degrees Celsius with a cold wind. It would be important to keep warm with the right clothes, but also to consume the proper amounts of fluids and nutrients along the way.

Together with my two running companions, (one from Norway, the other from USA), a total of 44,829 people completed the 42 km marathon this November day. My time was 6:23, which I was happy about. My goal was to complete it in five hours; but when everything is unknown and unfamiliar, one must be open to anything unexpected to happen. And it did!

I was not able to drink the cold water served along the way. My Norwegian companion Anita Toftner had to force-feed me when we had run about 23 km, because

she saw that I was tired. I was not allowed to run another step until I drank water and ate a banana. This worked!

When I run, I usually keep my companions close by me, which helps to keep me aware through the same rhythm of our legs and arms. But during the race, Anita had suddenly disappeared. Jeff, my American companion and I was worried about where she had gone. We continued about 10 more km before we thankfully found Anita. With approximately 9 km to the target, my knee said ‘stop’, and I had to limp-walk the rest of the trip.

I was not the first

Before arriving for the New York City Marathon, I thought that I was the first deafblind woman to run in this event; but I learned another had done this before me. In 1999, Maricar Marques, originally from the Philippines, was the first deafblind person to run the NYC marathon. Her time was 6:30. She is now a resident of the

USA and works at the Helen Keller National Center. We met her the Friday before the race. She told me when we met before the race that she had fought with a sore knee before her race in 1999. She is an impressive lady who para-jumps and cultivates many and varied activities. She has Usher Syndrome Type 1, born deaf with RP.

What is so special for us runners who have a disability, is that we wear yellow shirts with the name ‘Achilles International’. When the audience sees this, they cheer extra for us, which is something that keep us warm during these cold running hours.

The race went through five New York boroughs. The start is on Staten Island, with the first bridge, Verassano Bridge, being four kilometers long. This bridge has two levels, with the elite racers at the bottom floor and the others on the top. This was absolutely fantastic. From there we ran to Brooklyn and then on to Queens. At that point we came to Queens Bridge, located 23 km from the



Bedir Yiyit (Achilles Norway), John Planta (deaf American), Berit Oie and Harald Vik (deafblind Norwegian in his 18th marathon)



Anita
(personal
assistant)
and Berit
Oie

start. After that we ran through the Bronx and finally ending in Manhattan. How many bridges we ran across, I do not know? If only I would have had an interpreter; this would have put the icing on the cake!

Reflections about the need for an interpreter

I wish now to make a reflection about not having an interpreter during my marathon. When one spends so many hours carrying out such an activity, there is a lot happening. First, I got up at 4:30 AM Sunday morning to prepare myself for the course with the proper clothing and equipment; then had to take a bus to the starting area and wait for several hours before the 9 – 10 AM start. Everyone on the bus must be a runner, so my interpreters could not follow me to the starting area.

Luckily I could borrow an interpreter from my deafblind friend from Norway, Harald Vik, who was also in the race. His interpreter helped me with interviews and descriptions before the start of the race. Then there was the race itself. During this time I was at the mercy of my running companions. They tried the best they could to ensure that I would

finish the race and experience its atmosphere. They used haptic signals for smiles and applause from the audience and asking if I needed the toilet. Since none of them used tactile sign language, being social with the other running participants was not possible for me.

One of my questions to the interpreter after the race was whether there were many in the audience along the way as there had been at the start of the race. I could not see the two million spectators who usually cheer for the runners. The interpreter replied that yes there was the big crowd along the way as expected. Then I realized that was exactly what I had observed with my reduced vision and hearing. For me to experience two million people along a 42 km long route was quite impressive! After the race I asked Harald Vik to interpret how it was with various things along the race, and I was able to understand him through good interpretation.

Wishes for the future

As per my reflections indicated above, it is important to have an interpreter running along with me in a race. An interpreter is

important to let us know what is happening around us, as well as communicating during such a race. There were so many nice people to talk to, but I often come up short because I did not understand what was being said. When I run, I cannot use my hearing aids or Cochlear Implant. I tried using headphones, but my hearing is unfortunately too poor to use it.

I really hope that more interpreters in the future will participate and sign up to run with us in races, either for the entire marathon or parts of them.

I need to point out however that it is expensive to take interpreters abroad to participate in races or for tourist travel. For me to travel, I must pay my own expenses as well as that of an interpreter."

About Achilles

'Achilles' is an international organization headquartered in New York, which helps disabled people by providing companions for various activities. Achilles Norway is on Facebook.

About Berit

Berit Rasmussen Øie was born with a hearing loss and learned to speak when she was four years. Her visual impairment was discovered at the age of 18 years, following an accident. She was diagnosed several years later with Usher II. Berit currently has a severe visual impairment along with a hearing impairment that is worsening. She has just received a Cochlear Implant in one ear.

Berit is married with two children. She has an MSc in social sciences – with emphasis on physical education. An author of several reports, (available on www.lshdb.no), Berit previously worked as a consultant in Northern Norway. Currently she has her own business called: Active Deafblind! Ltd.

CHARGE Syndrome in Italy

The aims of the Lega del Filo d'Oro Onlus (non-profit organisation) are assistance, rehabilitation, and whenever possible, social integration of deafblind and multisensory impaired people within their natural family environment.

The Rehabilitation Centre of Osimo (near Ancona, Italy), is known as "A Special Unit for Deafblind and Multisensory Impaired Children and Adults". The Centre can accommodate 56 full time users, 15 day care users, while providing the opportunity for out-patient and home therapies such as physiotherapy and water therapy, etc. Some of the users at the centre have CHARGE Syndrome.

CHARGE syndrome is an autosomal dominant genetic disease caused by mutations or deletions/duplications of the CHD7 gene encoding Chromodomain helicase DNA-binding protein-7. The term 'CHARGE' is an acronym denoting the six clinical main features: Coloboma of the eye, Heart defects, Atresia of the choanae, Retardation of growth and/or development, Genital and/ or urinary abnormalities and Ear abnormalities with/without deafness. The occurrence of CHARGE syndrome is estimated to be 1 to 8500-12000 births. The condition is frequently diagnosed in the neonatal period because of the presence of multiple congenital anomalies and dysmorphic features. The mortality in CHARGE syndrome is greater



The child is involved in visual rehabilitation exercises

in the neonatal period and during the early childhood. Clients who survive are affected by different levels of disability, from mild to severe (e.g.'s: swallowing defects, respiratory problems, delayed speech and motor deficiencies) that require a multidisciplinary therapeutic approach.

Since 2005 the Rehabilitation Centre of Osimo, in collaboration with Regional Centre for Rare Diseases established at the Paediatric Clinic of the Polytechnic University of the Marche, has been taking care of more than forty clients with CHARGE Syndrome from all over Italy.

Our case load of 40 clients with clinical diagnosis of CHARGE, range in age from 0 to 35 years. Males and females are equally represented in this client group. Because of large number and the wide geographical distribution of

our clients, our case load can be considered representative of the Italian CHARGE syndrome population.

The care of children with CHARGE syndrome requires a complex management approach through the involvement of various professionals (pediatricians, medical specialists, physiotherapists, speech therapists, psychologists, educators, etc.) whose cooperation must be aimed at improving the quality of life of these individuals. Therefore one needs to have standardized guidelines to facilitate the rehabilitation approach.

At the Diagnostic Center of Lega del Filo d'Oro of Osimo, our clients are examined by a specific protocol of laboratory tests and equipment. This was specially designed by us through our experience and review of the literature.

We believe that our



A moment of rehabilitation

protocol is a valid and effective instrument for the diagnosis and monitoring of individuals with CHARGE syndrome. The protocol allows for an early diagnosis and the development of our individually based therapeutic program.

Among the diagnostic tests under the Protocol are the molecular exam and the neuro-imaging study of the brain and the ear; tests required for a global assessment of patients.

These exams include: a detailed examination of the cranial nerves and the middle and inner ear; psychometric tests and questionnaires for evaluating various skills (e.g.'s gross motor, fine motor, adaptive, social, language) that define a cognitive and behavioural profile typical for CHARGE syndrome.

The assessment of the

motor and behavioural profile as well as the study of the acquired developmental stages was carried out using a specific questionnaire: "Guida e progressi del bambino". La Guida ai progressi (The Handbook of Development) is a tool that can identify, in a simple manner and with a certain flexibility, the behavioural characteristics of multi-disabled children by comparing them with those of non-disabled children. The tool also makes it possible to identify the areas of strength and weakness of the subject and to monitor the development that takes place during psycho-educational interventions. Specifically, this questionnaire takes 10 areas into account: gross-motor skills; fine-motor skills; cognitive skills; socialization and play; eating; washing; dressing; sphincter control;

communication and expressive skills.

The investigation of every skill takes place through the verification of the achievement of specific developmental stages. The accessibility of this questionnaire means it can be administered by staff not specialised in the field of psychology.

For more information please contact Patrizia Ceccarani at ceccarani.p@legadelfilodoro.it

Authors:

Ceccarani, P¹, Santoro, L², Zallocco, F², Ficcadenti, A², Gabrielli, O²

¹Centro di Riavvilirzione lega del Filo d'Oro Onlus, Osimo

²Dip. di Scienze Cliniche Specialistiche, Sez. Pediatria, Università Politecnica delle Marche, Ancona

Report from Bernadette Kappen, Vice President Dbl

Deafblind International (Dbl) is a thriving and dynamic organization. As a member of Dbl I have personally witnessed the growth in the organization and the focused efforts to improve services to its members. The strategic plan is the work of many people and reflects the input of its members. The current strategic plan has helped improve the overall management and organizational functions of the organization.

As the digital age grew so did the needs for increased communication about Dbl. In the past it may have taken several weeks to share information or receive information from members. Now information is out within hours. Since the members are all around the world this type of access to communication is so important. As Dbl gets more involved with technology I believe our communication will continue to improve and bring us closer together. I think in the future we will be having more Skype meetings and Internet related seminars. Think about the information that could be shared if we develop a Facebook page or have a Dbl Twitter account. Currently all our programs are faced with challenging economic times. Many members would like to attend activities in person but the cost is often prohibitive. With the advances in technology we can help more individuals gain information and be connected to Dbl. Technology will never take the place of face to face meetings but it will give access to more people around the world.

We are ending an exciting four year period for Dbl. After many years of hard work we are finally a recognized Association and this is so important to fulfilling many of the goals on the strategic plan. Even though we are formally recognized we are the same supportive group of professionals. This is really what makes Dbl stand out among other professional organizations. Why is this? I have spoken in the past about the common goals we all have. We all deal with individuals who are deafblind and we don't have to explain what we mean to each other. We can immediately begin to support each other and share ideas. This is one distinction but the other is the level of volunteer work by the members.

Dbl pays a small fee to the organizations that provide the Secretariat and Information Officer and we get so much from them. Their contributions are well beyond the fee. The Secretariat responds on a daily basis to the needs of the members as well as responding to general requests for information. The Information Officer is working on a regular basis to gather information for the Dbl Review. The quality of the material provides so much information to members as well as allowing members to share their work. The website is also offering members access to information related to deafblindness and Dbl in general. On behalf of the all members of Dbl, I would like to thank CDBA and Senses Foundation for being so supportive of our efforts. I would also like to recognize William Green for his



“After many years of hard work we are finally a recognized Association and this is so important to fulfilling many of the goals on the strategic plan”

work on behalf of Dbl. William has always had a dream for a better Dbl and I believe he has achieved this and Dbl is stronger for his dedication to individuals who are deafblind and to Dbl as an organization.

I encourage you to think about the past four years and reflect on Dbl's achievements and also to think about the areas where we need more focus. This input is important to keep the strategic plan alive.

**Bernadette M. Kappen
Vice-President**

Dbl World Conference Scientific and Local Planning Committees

Meet together in Sao Paulo, Brazil

Sao Paulo, Brazil welcomed members of the 15th Dbl World Conference Scientific Committee during their 3 day meeting, February 25-27, 2011 organizing the program for the upcoming conference. Members were attending from Argentina, Brazil, Ecuador, England, Norway, Spain and the United States.

Members of the local planning committee also took the opportunity

to schedule one of their regular organizational planning meetings during this same period. This Committee consists of representatives from the hosting organizations from Brazil (Grupo Brasil, AdeFav, Mackenzie Presbyterian University and Centro Universitário Luterano), the conference secretary from Colombia (Ximena Serpa) and Stan Munroe from Canada representing the Dbl

Management Committee.

Several times during this period, both groups met together to coordinate their joint responsibilities for the upcoming conference.

Dbl would like to thank the various International organizations sponsoring individuals to participate in the Scientific Committee and the Brazil organizations for their dedicated work towards organizing the conference logistics.

Dbl Conference Scientific and Local Planning Committees celebrate their weekend accomplishments



2011 is proving to be an exciting and busy year for Dbl. At the Secretariat it has been a hive of activity and we are looking forward to playing our part in the preparations leading up to the World Conference in Sao Paulo, Brazil.

Meetings

We were very pleased to attend the ManCom meetings in Singapore in April. Corporate member, Koh Poh Kwang from the Lighthouse School was a most gracious host and his assistance in the lead up to and during the meetings was enormously appreciated. We thank Mr Koh and his wife for their hospitality and for allowing ManCom to visit the Lighthouse School and meet some of the students. ManCom made some good headway at the meetings and acknowledged the progress that has been achieved in line with the Dbl Strategic Plan. There is still a great deal of work to be accomplished in preparation for the Board and General Meetings in Sao Paulo and we thank the members of ManCom for their commitment to achieving the tasks in time to present to the Board in Sao Paulo.

Nominations for Dbl President & Vice Presidents

High on our list of priorities has been to assist the Nominations Committee in preparing the information for the election of the new Dbl President and Vice Presidents. Knut Johansen must be commended for his excellent work in what is a complex and very important matter. We are all excited to learn the outcome of the elections and congratulate the Nominations Committee for managing the process so well.



Bronte Pyett and Elvira Edwards
Dbl Secretariat

Strategic planning

A draft Strategic Plan 2012 - 2015 has been developed with the help of the Dbl Board. There is further work to be done to pull it all together and this Plan will then be presented to the Dbl Board for ratification in Sao Paulo. Once the plan has been agreed, it will shape the direction of Dbl for 2012 – 2015. The creation of this plan has been an enormous task and we would like to give special thanks to Gill Morbey for her excellent efforts in bringing it to life.

World Conference, Sao Paulo September 2011

It's hard to believe it has been almost four years since Perth hosted the last Dbl World Conference but we are very excited to be preparing for our attendance at the next World Conference in Sao Paulo. We are eager to spread the word about this significant event and hope that all our members will play their part in promoting the conference to colleagues and friends. Visit the conference website for all the information you need about the innovative program, registration, accommodation and all the wonderful things to do in and around Sao Paulo!

www.dbi2011.com.br

We will be setting up an information booth and will be proudly representing Dbl at the conference so please come and

say hello! We would love to hear about the work you are doing in your field and will be happy to assist you with any membership queries you may have.

Membership

This year we streamlined the membership renewal process and the renewal rate has been strong. Our members currently represent 32 countries and we are pleased to welcome new members from India, The Netherlands, Malawi, Canada, United Kingdom, Japan, Croatia, Germany and Italy in 2011.

Dbl relies on membership fees to fund the Organization and the work we do and we strongly encourage existing members to spread the word about Dbl and encourage other colleagues and organizations to become a member of Dbl. All the membership information can be found on the website www.deafblindinternational.org.

If you would like an update on the status of your membership please contact the Secretariat on secretariat@deafblindinternational.org and we will be more than happy to assist with your enquiry.

We hope you enjoy receiving the emails from the Secretariat informing you of news and events of interest. If you haven't heard from us in a while, please send us a message so we can be sure to have your email address recorded correctly.

We look forward to continued correspondence with members for the remainder of this year and hope to meet up with many of you at the World Conference in Sao Paulo.

Thank you

Elvira Edwards & Bronte Pyett
Dbl Secretariat



Deafblind International Individual Membership

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

Member details Membership No. _____

Title Surname First name _____

Organisation _____

Job Title _____

Address (Line 1) _____

Address (Line 2) _____

Town/City State/County _____

Zip/Post Code Country _____

Telephone no. Fax no. _____

(Please include country and area codes)

E-mail address: _____

Are you:

- a deafblind person
- a family member
- a professional

Does your organisation work primarily for/with:

- blind people
- deaf people
- deafblind people
- disabled people
- other (please specify) _____

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

DbI Review (please check one box in each category)

I would prefer to receive *DbI Review* on: paper disk*

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

Membership Fee please tick where appropriate

- I wish to pay for 4 years' membership at the **discounted rate** of €100

Corporate Membership

There are three tiers of Corporate Membership:

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

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

Mini corporates Annual fees between €100 and €250

Mini Corporate membership is available to interested organizations from the World Bank list of Heavily Indebted Poor Countries and Low Income Countries

- We would like to join DbI as a Large / Small / Mini Corporate Member

- Library membership fees €50 annually *(please delete as appropriate)*

We submit an annual fee of € _____

Corporate members are entitled to receive 25/10/5 copies respectively of *DbI Review*.

We would like _____ copies

Member Details: _____

Organisation _____

Representative _____

Address (Line 1) _____

Address (Line 2) _____

Town/City State/County _____

Zip/Post Code Country _____

Tel: Fax _____

(please include country & area codes)

Email: _____

Website: _____

How to pay?

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

- Payment method Bank Transfer Credit Card Cheque

A) Payment by Bank Transfer

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

Name of Bank: RABOBANK
 Address of Bank: Sint-Michielsgestel, The Netherlands
 Account Name: Instituut voor Doven: INZAKE DBI
 Account Number: 11.29.09.825
 Swift Address: RABONL2U
 IBAN: NL31 RABO 0112 9098 25

Date of Bank Transfer: _____

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

B) Payment by Credit Card

Card type: VISA American Express Mastercard

Card no:

Expiry date Name on card: _____

C) Payment by cheque

Please make cheques payable to "Stichting Viataal Zorg inzake DbI" and post to: Ton Groot Zwaaftink – DbI Treasurer, Theerestraat 42, 5271 GD, Sint-Michielsgestel, The Netherlands. If paying by Eurocheque, please make out cheque in euros.

Please fax this whole page to (08) 9473 5499 or return to: The Secretariat, Deafblind International, PO Box 143, Burswood WA 6100, Australia

Honorary Officers

President

William Green
Lega del Filo D'Oro
Via Montecerno 1, Osimo
60027
ITALY
Tel: +39 - 71 - 72451
Fax: +39 - 071 - 717102
Email: green.flo@usa.net

Vice-President

Bernadette Kappen
The New York Institute
for Special Education
999 Pelham Pkwy, Bronx,
New York 10469
USA
Tel: (718) 519 - 7000
Email: bkappen@
nyise.org

Treasurer

Ton Groot Zwaafink
Royal Dutch Kentalis
Theerestraat 42
Sint Michielsgestel
Noord-Brabant 5271 GD
NETHERLANDS
Tel: +31 73 55 88 280
Email:
T.GrootZwaafink@
kentalis.nl
Secretary
Elvira Edwards
Senses Foundation Inc.
PO Box 143
Burswood WA 6100
AUSTRALIA
Tel: +61 - 8 - 9473 5422
Fax: +61 - 8 - 9473 5499
Email: Elvira.Edwards@
senses.asn.au

Information Officer

Stan Munroe
Canadian Deafblind
Association
2652 Morien Highway
Port Morien Nova Scotia
B1B 1C6
CANADA
Tel: +1 - 902 - 737 - 1453
Fax: +1 - 902 - 737 - 1114
Email:
munroes@seaside.ns.ca

Strategy Group Leader

Gill Morbey
Sense
101, Pentonville Road
London N1 9LG
UNITED KINGDOM
Tel: +44 20 7520 0999
Fax: +44 845 127 0062
Email: Gillian.Morbey@
sense.org.uk

Large Corporate Members

BELGIUM

CBM
Catherine Naughton
Tel: 0032 (0) 2 2569000
Email: catherine.
naughton@cbm.org
Website: www.cbm.org

DENMARK

Interfond
Pierre J. Honore
Tel: +4563710218
Email: pjh.interfond@
mail.dk

FRANCE

French Deafblind Consortium
Maëlle Carre
Tel: +33 - 1 - 4627 4810
Fax: +33 - 1 - 4627 5931
Email: maellecarre.
anspa@gmail.com

GERMANY

German Deafblind Consortium
Wolfgang Angermann
Tel: +49 - 511 - 5100 815
Fax: +49 - 511 - 5100 857
Email: w.angermann@
taubblindenwerk.de

ITALY

Lega del Filo D'Oro
Rosanno Bartoli
Tel: +39 - 071 - 724 51
Fax: +39 - 071 - 717 102
Email: info@
legadelfilodoro.it
Website: www.
legadelfilodoro.it

NETHERLANDS

Joyce Wilson
Ton Groot Zwaafink
Tel: +31 73 55 88 280
Email:
T.GrootZwaafink@
kentalis.nl
Website: www.kentalis.nl

SPAIN

ONCE - Spanish National Organisation of the Blind
Pilar Gomez
Tel: +34 - 91 - 353 5637
Fax: +34 - 91 - 350 7972
Email: pgv@once.es
Website: www.once.es

SWEDEN

Resurscenter Mo Gard
Michael Karlsson
Tel: +46 8 753 59 40
Fax: +46 8 753 23 68
Email: michael.karlsson@
mogard.se
Website: www.mogard.se

UNITED KINGDOM

Sense Scotland
Joyce Wilson
Tel: +44 (0)141 429 0294
Fax: +44 (0)141 429 0295
Email: jwilson@
sensescotland.org.uk
Website: www.sensescotland.org.uk

Sense

Gillian Morbey
Tel: +44 20 7520 0999
Fax: +44 845 127 0062
Email: Gillian.Morbey@
sense.org.uk
Website: www.sense.org.uk

USA

Perkins School for the Blind
Barbara Mason
Tel: +1 - 617 - 972 7502
Fax: +1 - 617 - 972 7354
Email: barbara.mason@
perkins.org
Website: www.perkins.org

Networks

Acquired Deafblind Network

Liz Duncan
Email: Liz.Duncan@
sense.org.uk; linfo@adbn.org
Website: www.adbn.org

CHARGE Network

Andrea Scheele
University of Education
Heidelberg
Schützenstraße 13
64625 Bensheim
GERMANY
Tel: +496251939797
Email: andrea.scheele@
gmx.de

Communication Network

Ton Visser
P.O. Box 7
5270 BA SINT-MICHELSGESTEL
THE NETHERLANDS
Tel: +31 73 558 82 80
Email: ton.visser@
kentalis.nl; viss7973@
planet.nl

Congenital Deafblindness in Adults Network

Dominique Spriet
QUENEHEM BP 53 Rue du
mont saint Eloi
CALONNE RICOUART
62470
FRANCE
Tel: +33 - 3 - 21 61 16 16
Email: spriet@aftam.
asso.fr

Employment Network

Seija Troyano
Nakskovinkatu 8 and 9
78200 Vårkaus
FINLAND
Email: seija.troyano@
pp.inet.fi

EDbn

Ricard Lopez Manzano
Joanot Martorell, street
08014 Barcelona
CATALONIA - SPAIN
Tel: +34-678-712-619
Fax: +34-678-782-600
Email: rolopez@
sordocguera.com
Website: www.edbn.org

Latin America Network

Sandra Polti
ARGENTINA
Email: sandrapolti@
gmail.com

Outdoor Network

Joe Gibson
Sense Scotland
43 Middlesex Street
Kinning Park Glasgow
G41 1EE
UNITED KINGDOM
Tel: +44 (0)141 429-0294
Email: jgibson@
sensescotland.org

Rubella Network

Nancy O'Donnell
Helen Keller National
Center for Deaf-Blind
Youths and Adults
141 Middle Neck Road
Sands Point, NY 11050
USA
Tel: +516-944-8900 x326
Fax: +516-944-7302
Email: nancy.odonnell@
hknc.org

Siblings Network

Sabine Kersten
Koningsbeemdstraat 3
Lommel, B 3920
BELGIUM
Tel: +32 476 612 879
Email: siblingsnetwork@
gmx.net

Tactile Communication Working Group

Bernadette Van den
Tillaert
15175 Prairie Road
South Solon OHIO 43153
USA
Tel: +1-740-426-6728
Fax: +1-740-426-6728
Email: bernadettevan
dentillaert@tiscalimail.nl

Usher Study Group

Tamsin Wengraf
Newplan House,
41 East Street
Epsom Surrey KT17 1BL
UNITED KINGDOM
Email: Tamsin.Wengraf@
sense.org.uk

Small Corporate Members

ARGENTINA

Cooperative Association "Look with the Heart" (COOPA)
Beatriz Angelica Zoppi
Tel: +54 - 2302 - 430 690
Fax: +54 - 2302 - 434 274
Email: beazoppi@yahoo.com.ar

Perkins International - Latin America Office

Graciela Ferioli
Tel: +54 351 4234741
Fax: +54 351 4234741
Email: hperkins@fibertel.com.ar

AUSTRALIA

Senses Foundation Inc.
Elvira Edwards
Tel: +61 - 8 - 9473 5422
Fax: +61 - 8 - 9473 5499
Email: Elvira.Edwards@
senses.asn.au
Website:
www.senses.asn.au

Able Australia

Celestine Hare
Tel: +61 - 3 - 9882 7055
Fax: +61 - 3 - 9882 9210
Email: Celestine.hare@
ableaustralia.org.au;
info@ableaustralia.org.au
Website: www.
ableaustralia.org.au

Australian Deafblind Council (ADBC)

Alisa Wills
Tel: +61 3 9882 8596
Fax: +61 3 9882 9210
Email: info@deafblind.org.au
Website:
www.deafblind.org.au

The Royal Institute for Deaf and Blind Children

Alan Baynham
Tel: +61 - 2 - 9872 0366
Email: alan.baynham@
ridbc.org.au
Website: www.ridbc.org.au

The Forsight Foundation for the Deaf/Blind

Trish Wetton
Tel: +612 9872 9000
Fax: +612 9872 9111
Email: forsiht@
bigpond.com

AUSTRIA

Österreichs Hilfswerk für Taubblinde
Christa Heinemann
Tel: +43 - 1 - 6020 8120
Fax: +43 - 1 - 6020 8127
Email: cheinemann@
zentrale.oehbt.at
Website: www.oehbt.at

BRAZIL

Grupo Brasil de Apoio ao Surdcego e ao Múltiplo Deficiente Sensorial
Shirley Rodrigues Maia
Tel: +55 - 11 - 5579 5438
Fax: +55 - 11 - 5579 0032
Email: Contato@
grupobrasil.org.br
Website: www.
grupobrasil.org.br

CANADA

CDBA National
Tom McFadden
Tel: +1 905 319-9243
Fax: +1(905) 319-2027
Email: tmcfadden@
sympatico.ca
Website: www.
cdbanational.com

Deafblind Ontario Services

Roxanna Spruyt-Rocks
Tel: +1 - 905 - 853 - 2862
Fax: +1 - 905 - 853 - 3407
Email: excedir@
deafblindontario.com
Website: www.
deafblindontario.com

Resource Centre for Manitobans who are Deaf-Blind (RCMDB)

Jane Sayer
Tel: 1-800-855-0511
TTY: 1 204 284 2531
Fax: +204 477-1390
Email: jsayer@rcmdb.net
Website: www.rcmdb.mb.ca

Rotary Cheshire Homes

Cindy Accardi
Tel: +1 - 416 - 730 - 9501
Fax: +1 - 416 - 730 - 1350
Email: rchdirector@
rogers.com
Website: www.
rotarycheshirehomes.org

Canadian Deafblind Association (Ontario Chapter) Inc.

Cathy Proll
Tel: +1 - 519 - 759 - 0520
Fax: +1 - 519 - 759 - 1425
Email: cprroll@
cdaontario.com
Website: www.
cdaontario.com

The Lions Mclnnes House - Group Home for Deafblind Persons

Joan Brintnell
Tel: +1 - 519 - 752 - 6450
Fax: +1 - 519 - 752 - 9049
Email:
LionsMclnnesHouse@
rogers.com

CHINA

HONG KONG

Resource Centre for the Deafblind
Doreen Mui
Hong Kong Society for
the Blind
Tel: (852) 2778 8332
Fax: (852) 2777 6559
Email: doreen.mui@hksb.org.hk

CYPRUS

Pancyprian Organization of the blind
Christakis Nikolaides
Tel: +357 22495395
Email: pot@logos.cy.net

DENMARK

Center for Deaf
Else Marie Jensen
Tel: +45 44 39 12 50
Fax: +45 44 39 12 63
Email: emj@cfb.dk
Website: www.cfb.dk

The National Centre of Knowledge on Disability and Social Psychiatry

Marianne Disch
Tel: +45 - 41 - 93 24 65
Email: mdi@
servicestyrelsen.dk
Website: www.
dovblindfodt.dk
Centre for the Deafblind
Lars Soby
Tel: +45 99 31 87 00
Email: laejs@rn.dk
Website: www.dbc.rn.dk

Nordic Centre for Welfare and Social Issues

Henriette Hermann
Olesen
Tel: +45 - 96 - 47 16 00
Fax: +45 - 96 47 16 16
Email: henriette.olesen@
nordicwelfare.org
Website: www.
nordicwelfare.org

FINLAND

The Finnish Deafblind Association

Heikki Majava
Tel: +358 - 9 - 54 95 3513
Fax: +358 - 9 - 54 95 3517
Email: heikki.majava@
kuurosokate.fi
Website: www.
kuurosokate.fi

GERMANY

Benzthaim Schule-Blindeninstitut
Jutta Wiese
Graf zu Bentheim Schule-
Blindeninstitut
Tel: +49 9312 092 119
Fax: +49 931 2092 1233
Email: juwiese@gmx.de
Website: www.
blindeninstitut.de

GREECE

Hellenic Association of Deafblind "The Heliotrope"

Diamanto-Toula Matsa
Tel: 30-210-6440689
Fax: 30-210-6440689
Email:
diamatsa@gmail.com

ISRAEL

Nalaga'at Center

Adina Tal
Tel: +972 3 633 08 08
Fax: +972 3 682 37 15
Email: adina@nalagaat.org.il
Website:
www.nalagaat.org.il

INDIA

Sense International (India)

Akhil Paul
Tel: +91-79-26301282
Fax: +91-79-2630 1590
Email: akhil@
senseindia.org
Website: www.
senseindia.org

ITALY

Danish Parents Association

Lone Poggioni
Tel: +39 075 51 79 413
Email: esbjerg@alice.it

NETHERLANDS

Bartimeus

Raad van Bestuur
Tel: +31 - 343 - 526 650
Fax: +31 - 343 - 526 798
Email: info@bartimeus.nl
Website:
www.bartimeus.nl

Kalorama

M. Verseveldt
Tel: +31 24 684 77 77
Fax: +31 24 684 77 88
Email: M.Verseveldt@
kalorama.nl; info@
kalorama.nl;
Website:
www.kalorama.nl

Royal Visio

Kees Kuypers
Tel: +31 - 55 - 5800 695
Email: keeskuypers@
visio.org
Website: www.visio.org
University of Groningen
Marleen Janssen
Tel: +3150-3636575
Email: h.j.m.janssen@
rug.nl

NORWAY

AKS (Andebu Kompetanse- & Skolesenter)
Anne Lise Hoydahl
Tel: +4733438600
Email: anne.lise.hoydahl@
signo.no
Website: www.statped.no/aks

Andebu Dovblindesenter

Knut Johansen
Tel: +47-33-438 700
Fax: +47-33-438 720
Email: knut.johansen@
signo.no

Eikholt

Roar Meland
Tel: +47 3288 9050
Email: roar.meland@
eikholt.no
Website: www.eikholt.no

Regional resource Centre for Deafblind, Statped

Evabrilt Andreassen
Tel: +47-55-923 485
Fax: +47-55-923 491
Email: evabrilt.
andreassen@statped.no
Skaadalen Resource Centre
Else Marie Svingen
Tel: +4722703702
Fax: +47 - 22 703 715
Email: Else.Marie.
Svingen@statped.no
Website: www.statped.no

RUSSIA

Rehabilit Centre for Deaf "Otofon"

Olga Smirnova
Tel: +7495 4651 740
Fax: +7495 456 0619
Email: otofon@otofon.ru
Website: www.otofon.ru

SINGAPORE

Lighthouse School
Koh Poh Kwang
Tel: +65-2503 755
Fax: +65-2505 348
Email: kohpohkwang@
lighthouse.edu.sg
Website: www.
lighthouse.edu.sg

SPAIN

Spanish Federation of Deafblindness (FESCOE)
Ricard Lopez i Manzano
Tel: +34 93 331 7366
Fax: +34 93 331 4220
Email: fescoe@fescoe.org
Website: www.fescoe.org

SWEDEN

The Swedish Resource Centre for Matters Regarding Deafblindness

Michael Karlsson
Tel: +8 753 5940
Email: michael.karlsson@
mogard.se
Website: www.nkcbd.se

SWITZERLAND

SZB Beratungsstellen für hörschbehinderte und taubblinde Menschen

Made Müller
Tel: +41 (0)44 444 10 81
Fax: +41 (0)44 444 10 88
Email: mueller@szb.ch
Website: www.szb.ch

Tanne, Schweizerische Stiftung für Taubblinde

Jette Ehrlich
Tel: +41 - 44 - 714 7100
Fax: +41 - 44 - 714 7110
Email: henriette.ehrlich@
tanne.ch
Website: www.tanne.ch

UNITED KINGDOM

Sense International

James Thornberry
Email: james.
thornberry@
senseinternational.org
Website: www.
senseinternational.org

UNITED STATES OF AMERICA

The New York Institute for Special Education

Bernadette Kappen
Tel: (718) 519 - 7000
Fax: 11+718-881-4219
Email: bkappen@
nyise.org
Website: www.nyise.org

Overbrook School for the Blind

Jackie Brennan
Tel: +1 - 215 - 877 0313
Fax: +1 - 215 - 877 2466
Email: jackie@obs.org
Website: www.obs.org

VEZUELA

SOCIEVEN, Sordociegos de Venezuela, A.C.

Maria Luz Neri de Troconis
Tel: +58 - (212) - 952.94
Fax: +58 - (212) - 952.63
Email: maluzneri@
socieven.org
Website:
www.socieven.org

Mini corporate members

NEPAL

Renu Lohani
Society of deafblind Parents,
SDBP
Tel: 977-1 4600450
Fax: 977 1 4600450
Email: rlohani@wlink.com.np

MALAWI

Ezekiel Kumwenda
African Federation of the
Deafblind
Tel: 00 (265) 999 952 391/888
852 391
E-mail: kumwendaezekiel@
yahoo.com