



Nalaga'at Theatre Group – Prince Rooster

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

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

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

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

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

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Cover: Cast of Prince Rooster

A message from the president

Dear Friends and Colleagues,

It seems very strange for me to be writing on this page. William Green has filled this slot for many years. William's commitment and contribution to the world of deafblindness and Dbl has been immense. Still I'm delighted to say that William will continue on the Management Committee as immediate Past President.

I am writing this as a very 'new' President but not so new to the world of deafblindness or Dbl. Hopefully I am known to many of you and very much look forward to meeting more friends. It's also a great joy to introduce our new and refreshed team. Bernadette Kappen, recognised at the Dbl world conference in Sao Paulo for her 'significant contribution' is of course our Vice President along with Carolyn Monaco of the Canadian Deafblind Association. Ton Grootzwaaftink from Kentalis was reaffirmed as our treasurer at the September AGM. Stan Munroe of course, remains our information officer and proud editor of this review and we are all organised by Elvira and Bronte and many thanks to Senses for their continued role as our secretariat. So that's our team along with the Dbl Board and of course all of you.



For those of you who attended the XV Dbl World conference in Sao Paulo this past September, 2011, you will agree it was indeed a wonderful event. I know there were many who couldn't attend but over the coming months more information will be published. Of course this edition of the Dbl Review will begin to give you some of the flavour of the conference. We must certainly extend a huge thanks to all our Brazilian colleagues (and their volunteers) from ADEFAV, Grupo Brasil and AHIMSA who worked so incredibly hard in such a short period of time; and they should be proud of such a brilliant achievement.

The content of the many presentations, workshops and plenary sessions was really high quality and as usual there were some magical moments. One such moment was the announcement of the new parents and carers world

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organisation, WCPDB. I was privileged to speak at the pre conference for families and of course met so many wonderful parents. There were also fantastic professionals who always give so much and work way beyond the 'call of duty'.

Looking to the future we have our strategic plan and I am delighted that Lucy Drescher from Sense is going to assist William Green in supporting our very important Networks. The next meeting of the Management Committee will take place 11-13th February, 2012 in Lille, France, during which time we will also meet with the local planning committee for the 2013 Dbl European Conference. The

Board of Dbl is planning their next meeting in New York on the 4th and 5th of May 2012.

I hope you enjoy this edition of the magazine; as usual Stan has worked hard in pulling so many wonderful stories together into a journal we are exceptionally proud of. Still the magazine is only as good as the content. When I look at the range and depth of our work in deafblindness, I see plenty of potential material for publication. In addition to that, knowing that so many people are committed to this field makes me exceptionally proud of being your new President.

With the best of all wishes
Gill Morbey

EDITORIAL

Dear Friends,

Assembling this current edition together has been a very special experience for me. You will notice that much of this edition is from the extremely successful XV Dbl Conference held in late September 2011 in Sao Paulo, Brazil.

The Brazilian conference was a great opportunity for Latin Americans involved in deafblindness to participate in a world conference closer to home - and in their more familiar languages.

There are a couple of things I wish to take this opportunity to say about the conference and about related articles in this edition.

First is about inclusion, the excellent theme of this

conference. For those attending, a casual look around the various venues one could see the many varieties of communicating going on; communication being a basic key to inclusion. Lex Grandia's plenary accompanied by the two respondents from Brazil, highlighted the landmark UN convention as being the foundation ensuring deafblind persons' achieving their 'lifetime of opportunities'.

There are several other examples of 'inclusion for



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Families

Event Sponsored by ABRAPASCEM – Brazilian Association of Parents and Friends of Deafblind and Multiple Sensory Impaired People

ABRAPASCEM organized a Families Pre Conference on September 25, 2011, prior to the XV Dbl World Conference. Forty participants were in attendance from nine countries: Argentina, Austria, Brazil, Canada, Chile, Paraguay, Spain (Catalonia), UK (Scotland) and Venezuela. Brazilian families were in attendance from the states of Federal District of Brasília, Mato Grosso, Mato Grosso do Sul, Rio Grande do Sul, Rondônia, and São Paulo.

The pre-conference started with a dedication to pioneer

parents Norman Brown (UK) and Carlos Picasso (Argentina), remembering their efforts and restless leadership work in their own countries, outlining the support they provided to many parents in Latin America, and elsewhere, as well as their encouragement to establish country based associations.

Speakers were invited from Argentina (Áurea Soza), Brazil (Susana Araújo and Márcia Maurílio), Canada (Stan Munroe), Spain-Catalonia (Ricard Lopez) and the UK-Scotland (Gill Morbey) to tell about

the challenges of families, experiences and the successes of the parents organizations in their own country.

One might conclude from the presentations and discussions that families of deafblind people all over the world face the same difficulties. Family members need very much strength in the face of these difficulties. It is important that family members join together to develop and achieve objectives that ensure that their deafblind children are included in society as full and active members regarding their specific needs in health,

Family Pre Conference Presenters: L to R – Stan Munroe, Ricard Lopez, Aurea Soza, Marcia Maurilio, Dwain McLean, Gillian Morbey and Susan Aroaz





Brazilian parents discussing their family situations

education, leisure and employment.

Near the conclusion of the workshop, parents from different states in Brazil briefly explained their situation and reflected a bond they share with the association ABRAPASCEM.

It appeared that that the participants were very happy

with this meeting and were pleased with the opportunity to reinstate past friendship bonds and create new ones.

A subsequent outcome of this parent's conference was an informal meeting to discuss forming an international organization of parents of deafblind and multi-sensory disabled

“It appeared that that the participants were very happy with this meeting and were pleased with the opportunity to reinstate past friendship bonds and create new ones”

persons. An announcement of the formation of this organization was made during the closing session of the World Conference on October 01, 2011.

As parents we should be the safe harbour for our children; we should develop as a family to fulfill this task.

Susana Maria Mana de Araújo

INDEPENDENT DEPENDENCY LIVING IN TWO REALITIES

The 9th Conference of Acquired Deafblindness Network
Lund, Sweden in November 7-10, 2012

www.skane/adbn2012

Evaluation of Deafblind and Multi Sensory Disabled People

Dr. Jan van Dijk of the Netherlands and Dr. Catherine Nelson of the University of Utah in the United States were pleased to have been given the opportunity to present a two day presentation on their Child-Guided Assessment Method for children who are Deafblind at the Pre Conference preceeding the XV Deafblind International World Conference in Sao Paulo, Brazil, September 25-26, 2011. Approximately 50 persons attended the two day event, from such countries as Argentina, Brazil, Canada, Netherlands, Spain (Catalonia), UK (Scotland), USA and Venezuela. The two-day event has been summarized below.

Understanding Children who are Deafblind Through Child-Guided Strategies *Jan van Dijk, PhD and Catherine Nelson, PhD*

Within the presentations were descriptions of the methods utilized in the assessment as well as the framework used to determine child strengths, needs, and future directions for intervention. On each workshop day, Dr. van Dijk conducted a live demonstration of the assessment with a child while Dr. Nelson explained to the audience what he was looking for and highlighted specific child behaviors. After each assessment, the audience was invited to use the framework to formulate instructional goals for the children. Later in the conference, Dr. van

Dijk assessed a third child to give participants another opportunity to gain knowledge about how to assess children who are deafblind using this unique approach.

As was explained in the workshop sessions, each assessment using the Child-guided Assessment method begins by talking with caregivers and teachers to find out information about the child including child interests, likes, dislikes, strengths, and needs. It is also important to find out what parents and teachers hope to learn from the assessment and then every attempt

is made to ensure that answers are provided after the assessment. The assessor then uses the child's interests as a guide and carefully follows the child's interests and movements. Neuroscience has taught us that special neurons reside within the brain and these neurons work together to form the mirror neuron system. As we imitate what we see others do, the mirror neurons allow us to empathize with them as we "mirror" their movements and emotions. For example, when we see a person yawn, we often yawn shortly afterward and when we

Dr. Jan van Dijk, Dr. Catherine Nelson (far right) along with several preconference attendees





Dr. vanDijk along with parent and child following an assessment

see another's eyes fill with tears, we feel like crying as well. In each workshop session, participants were able to see Dr. van Dijk completely engross himself in the child's interests as he followed their movements, vocalizations, and interests. In this manner, he utilized the mirror neuron system to better understand the child's meanings, emotions, and choices. He then adapted his interests and emotions to that of the child. Turn-taking conversations were established through the imitation of child actions and these exchanges were used to establish pleasurable routines. Each of the child's behaviors were responded to as communication and throughout, the child was given the opportunity to express whether he or she wanted the routine to continue, stop, or take another direction. Varying sensory channels were used to examine actual use of sensory channels. Dr. van Dijk explained that even though a child might be labeled "deaf," hearing should not be ignored and workshop participants clearly saw each of the children respond to Dr. van Dijk's singing.

As the assessments continued, Dr. van Dijk built upon the interests of the children and then had them

follow his initiations. Through this activity, assessors were able to learn more about the children's areas of need and also their skills in memory, anticipation, social interaction, communication, and problem solving. For example, in the first assessment of a lovely girl with Congenital Rubella Syndrome who was very interested in a bottle

“Drs. Van Dijk and Nelson feel it is important for audiences to really experience the assessments in a personal manner.”

that contained colored sparkles, Dr. van Dijk built upon her interest by pouring some of the water into a cup and passing the cup to her mother and having her, in turn, pass it back to him. In this manner, he was able to get the child to imitate what he did and also participate in a social turn-taking routine that could be functional and enjoyable in daily life. The audience was amazed when the girl came back after lunch and without any prompting, went to

the front of the room and poured more water into a cup.

Although the assessments were only about one hour in length, participants in each session were able to gain much information about the children and together with the presenters, formulate an assessment summary. They then were able to state educational goals that built upon the child's learning styles and strengths as well as his or her needs.

Although one of the tenants of the assessment is to assess in an area that is comfortable to the child, Drs. Van Dijk and Nelson feel it is important for audiences to really experience the assessments in a personal manner. In order to help the child feel comfortable, parents were active participants in the assessments, and as always in this assessment method, the child and family desires were respected throughout. The Child-guided Assessment process does not use any standard materials but instead depends on the assessor's skills in going to the child's world as learning is facilitated. As a result of this workshop, the presenters hope that workshop participants will practice the techniques learned and enjoy and learn from the children they work with.

Tactile Communications

Event Sponsored by Tactile Communications Network

The Dbl Tactile Communication Network presented a Pre-Conference 'Landscape of Touch' (preceding the 15th Dbl World Conference) on September 25 and 26, 2011, in Sao Paulo, Brazil.

Approximately 60 persons from 14 countries (Argentina, Australia, Brazil, Canada, Chile, Columbia, Denmark, France, The Netherlands, Norway, Sweden, Turkey, UK, USA and Venezuela) were in attendance, supported by 15 interpreters.

The incredible organization and generosity of Grupo Brazil, the Prefeitura of Sao Paulo, CAPES (Coordenação de Aperfeiçoamento de Pessoal de Nível Superior) and Dbl made the preconference possible. The network members and the participants were grateful for this opportunity!

Please note that through this report, I will also make references occasionally to the Dbl World Conference and to the network meeting held on September 27, 2011.

The members of the network, Bernadette Van Den Tillaart, Gunnar Vege, Barbara Miles and Paul Hart, collaborated on producing the DVD 'Landscape of Touch' and preparing materials for the pre-conference in Brazil. In our previous

Dbl Review Network News we described the content of the DVD.

The participants of the pre-conference formed a diverse group. They came from many continents, and many of them were not familiar with the work of this network. The sensory perception of the participants varied across the whole spectrum and so did the means of communication used. They also brought in a full range of educational, personal, family, rehabilitative and administrative experiences with deafblindness. After we showed the movie, the responses addressed many topics. Among them were a gradually increased 'feeling' of the images on one's own skin and in one's own body, hands and feet; pace; examples of tactual experiences and communication; repetitions; characteristics of the tactual world; emotions that were evoked by the movie; availability of the hands and feet; personal bodily boundaries; and the richness of the tactual landscape. Through guided imaginary, the movie, presentation of theoretical foundations, exercises, sharing ideas and practical implementations, the participants moved with the

network members closer and deeper into the tactile landscape.

Sao Paulo is located on the southern hemisphere; the change of season after traveling was striking from a sensory perspective. The birds twittered and moved quickly, loud and agitated to build nests in Sao Paulo's park, unlike the northern hemisphere's lazy after-summer birds' sounds. The patches of color were bright purple and pink, so different from the golden fields and ochre lining of ditches in the north. Most branches still were bare, unlike bushes and trees full with leaves to embrace wide. The sun felt forcefully warm, pulling the seedlings out of the earth and transforming the color of our skin; what a change from a sun which warmed up only slightly the early fall chill. The air currents felt crisp, not as dusty. It carried scents of some fresh leaves and early blooms, incomparable to the sun soaked heavy fragrances of end-of-the-summer flowers. We walked upon earth that still felt wintery harsh, remembering from home the moving textures of the first fallen leaves underfoot. Within this seasonal experience of change, the landscape of the hand of the other felt even more familiar.

Participants and presenters attending 'Landscape of Touch'





Presenter Barbara Miles



Presenter Bernadette van den Tillaart

The tactile landscape exists around and right in front of us, but often is dominated and masked by all the visual and auditory information in cultures focused on these distant senses. During the pre-conference many participants made a paradigm shift. One participant reflected on an exercise experience and within her response the audience literally followed her mental shift in awareness and her realization of the impact. When tactual shared experiences become meaningful for both partners in an interaction, this becomes the foundation for exploration of new environments, development of meaningful communication and well-being, and the building of joyful friendships. The diverse cultural backgrounds of the participants brought ideas that touched on what was acceptable at one place and not at the other, and we discussed how these ideas could be attuned to be respectful of the local ethics.

During the Dbl World Conference following our pre-conference, many key note speakers and other presenters included a focus on the tactile sense, ranging over many different topics. Among the participants, many considered themselves deafblind. The role of touch was evident everywhere and among many.

During our Network meeting later during the conference, we showed 'Landscape of Touch'.

The responses were very similar to those in the pre-conference. In addition, they commented on the different layers that were touched upon in this movie.

In the reflections participants mentioned that in their work they did simulation experiences of daily activities and some of them offered families and educational staff contact with a deafblind person who could describe how he/she experienced the world. They did or would like to start sharing video examples.

We opened the discussion to the Dbl members regarding the future activities of the network.

One of the first spontaneous responses to 'Landscape of Touch' in the preconference as well as in the network meeting was "Where can I get this movie?" The DVD will become available in the spring of 2012. The movie will be made accessible for persons with a sensory impairment. Those who are interested will be able to order the DVD for a not-for-profit price through the websites of one or more of the organizations who graciously sponsored our work since the beginning of the network (Sense Scotland, Perkins International, Andebu Dovblindesenter). There will be a link at the Dbl website as well. If you would like to receive a notification when the DVD is available, please send an email to the address below.

Those present in the network

meeting and in the preconference expressed a need for training materials. In these materials, the trainer would find the introduction to the movie, additional video's, texts and presentation suggestions to address the different layers of the DVD. The network members are working on training materials that would accompany the DVD.

The participants indicated they also would like to receive updates on the network activities and we created a temporary email list.

Some participants expressed that they would like to engage more actively with the network and we would like to hear from them! We are keen to involve new fellow travelers on this exciting journey into the world of touch, and this may be in a variety of capacities.

We truly would like to thank Vula Ikonmidis, Ximena Serpa, Shirley Maia and their colleagues, Stan Munroe, the Dbl Conference Committee and the Prefeitura of Sao Paulo for their tireless efforts, communication and support to organize the preconference. Then, on a fun note, Luciana, Marianna and Miguel made it possible for many of us to experience the authentic samba of Brazil and they provided us with the cultural (Brazilian, deafblind) idea that 'time is an opinion'. The focus on deafblindness in these seven intense conference days might have given an increased surge of awareness and focus on the opportunities possible in Brazil. We hope that the deafblind organizations and the Prefeitura of Sao Paulo experienced this conference as a 'Brazilian Spring' for their deafblind community.

If you would like to receive network updates, or if you are interested in active involvement with this network, just send an email to us.

bernadettevandentillaart@tiscailmail.nl

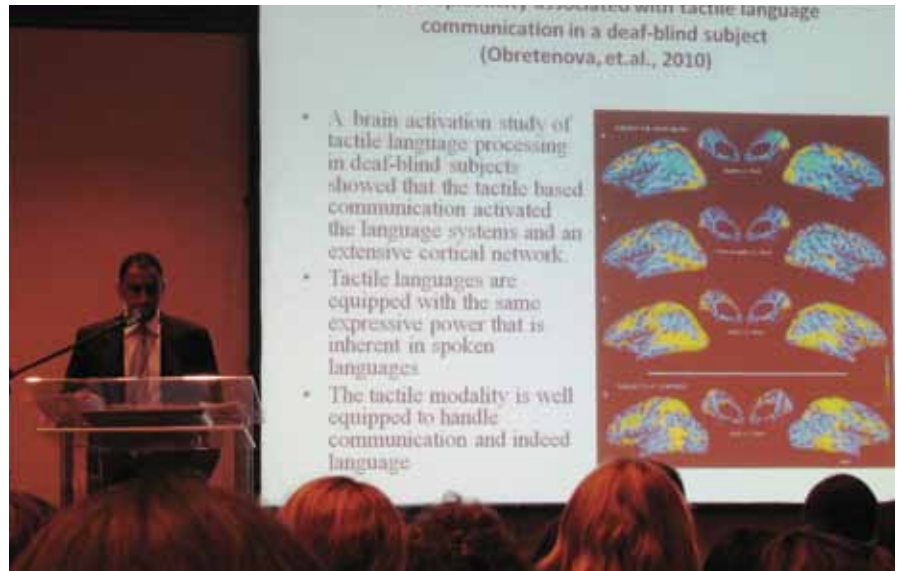
Pediatric Rehabilitation:

Specific focus on the needs of children with deafblindness

Pediatric rehabilitation is a form of rehabilitation which focuses specifically on the needs of children with severe disorders of a variety of types. Generally speaking, a pediatric rehabilitation program is interdisciplinary based, coordinated and focuses on outcomes. However, in the last decades pediatric rehabilitation programs have moved from impairment based and child-centered to functional-based and family oriented management strategies. These various pediatric programs include working closely with families, schools and community services to help plan and provide coordinated pediatric rehabilitation services.

Nowadays professionals working with a pediatric population recognize the interaction between intrinsic and extrinsic factors that shape the developmental processes. Intrinsic factors include the aspects of genetics, biology or neurobiology, while extrinsic factors involve the aspects of the environment and interactions between child-parent and child-staff. In addition to a developmentally appropriate approach in rehabilitation, pediatric rehabilitation programs focus on: Preventing further impairment, complications and delays, Enhancing child-parent relationships & the quality of life in children, Reducing limitations in areas such as mobility or self-care & Maximizing development, learning and communication.

The first step in any pediatric rehabilitation aimed at children with deafblindness is to identify deafblindness as a unique and



Jude Nicholas presenting plenary

diverse disability. This is due to: the type of deafblindness (congenital, early onset or late onset with hearing impairment and/or visual impairment), the cause of deafblindness (infection, toxic, genetic or other causes), the presence of additional disabilities (such as motor disabilities or multiple disabilities) and the wide range of sensory capabilities (residual vision, residual hearing, and the use of active touch)

The second step is to recognize that children with deafblindness have unique learning and communication challenges, and therefore there is a need for specific functional methods for assessing sensory capabilities and learning skills, and also a need for developing appropriate interventions to enhance and maximize the deafblind child's communication and language development.

Although children with deafblindness may use

residual vision or hearing for communication and language development, deafblind children use active touch and body movements in ways that no one else does to explore objects and the environment, to perceive feelings, to act and to communicate. This can mean that a congenital deafblind child may be better equipped at perceiving the world from a tactile perspective.

The two phenomena – active touch and communication – and their relations, are necessary to consider when understanding touch as a mode of communication.

When regarding rehabilitation or intervention based on the tactile medium two apparently dissociable aspects of tactile communication competencies emerge; a) The deafblind child's tactile abilities and functional possibilities, such as the functions of the tactile processing system and b) The essential relationships

accessible and meaningful to each deafblind child such the communication context and the competent communication partner, respectively, (a) intrinsic and (b) extrinsic factors (see fig.1 below). Competent communication partners are persons who are able to interact and communicate in terms of each deafblind person.

In the case of congenital deafblindness it is utterly necessary to point out the significant dynamic and reciprocal interactions between intrinsic and extrinsic factors. This means that the tactile processing function of the deafblind child is not intrinsic or individualistic but built up in interactions with the world and people around the child. Thus, understanding the world and one's relationship to it, the essence of tactile sensory information processing, is not easily separated from the deafblind child's communicative capabilities. Personal factors and environmental events operate as interacting determinants of each other. Put in other words, if and when interaction and communication is not established or developed, there is a high risk for not recognizing the potential of the child with deafblindness.

Active touch does not constitute a primitive or inferior sensory modality when compared with



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vision and audition. Typical tactile cognitive functions have been systematically under-estimated in scientific research.

It is through the sense of touch we process the tactile information of our environment. Touch messages are the first link in the "chain" of information properties required for the processing of tactile information. The tactile processing system reflects a continuum of attributes along the aspects of tactile sensation, tactile perception and tactile cognition.

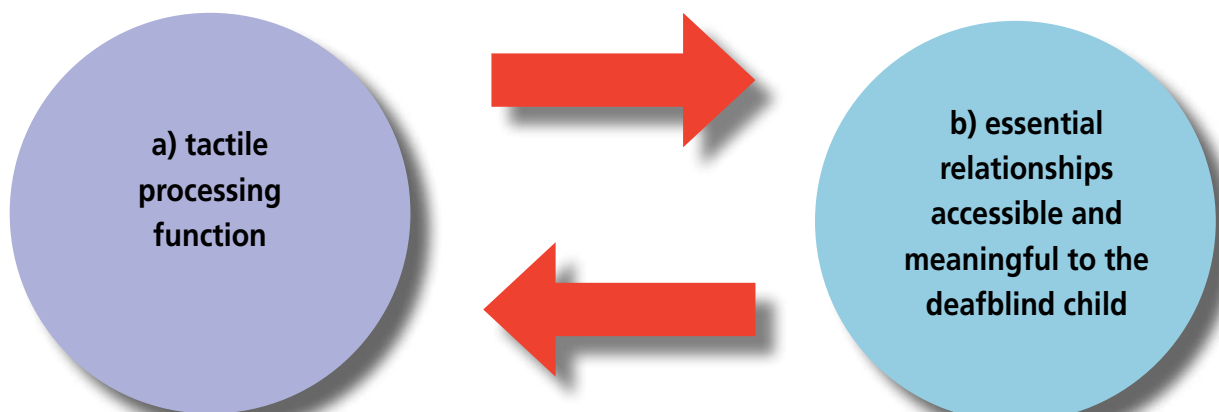
The attributes of tactile representations in the human information processing system consists of the following: (1) low-level tactile sensory processing

which includes touch sensations proprioceptive sensations, kinesthetic senses of bodily movement and balance, (2) tactile motor functioning which includes manual exploration and manipulatory skills, (3) tactile-perceptual processing which includes the discrimination of the tactile features of objects (texture, substance, size, or shape), tactile-spatial perception, (4) high-level tactile cognitive processing which involves tactile attention, tactile processing speed, tactile working memory, tactile learning, tactile memory and tactile language.

Neuroscientific research shows a reciprocal relationship between low-level tactile sensory processing and high-level tactile cognitive processing in the discriminative touch neural pathway. Tactile sensations from hands and body pass through the spinal cord, medulla and thalamus reaching the somatosensory cortex, and is then divided into distinct streams of information processing. This gives evidence for a complex and rich capacity sensory processing system. Such processing capacity permits our brains to analyze complex tactile information in one-tenth of a second, and allows us to experience the richness of the world.

Likewise, brain activity studies of tactile working memory,

Figure 1.
Significant dynamic and mutual interactions between intrinsic and extrinsic factors



which is a cognitive process that enables us to keep the relevant tactile information active for task performance over a short period of time, have identified the involvement of prefrontal cortical areas implying higher stages in the processing of tactile sensory information (Kostopoulos et al., 2007). The same brain areas are also involved during tasks of visual or auditory working memory. These frontal functions are domain general, possibly because of the extensive reciprocal connections with virtually all other brain regions, integrating information from these regions (Stuss, 2011).

Working memory is what enables us to keep several pieces of information active while we try to do something with them. Working memory is a critical component of cognitive architecture and plays a major role in reasoning, problem solving and language. There is increasing evidence suggesting that working memory and language learning are strongly linked.

Recent studies show significant associations between working memory and language learning. For instance, between working memory and children's emerging language abilities (Engel de Abreu, et al., 2011); between working memory and sign language (Wilson & Fox, 2007). However, there is still a need for research studies to understand the relation between tactile working memory and the deafblind child's communicative or language capabilities within an interactional or dialogical perspective.

Furthermore, neuroanatomically speaking, the strong link between the processing of tactile information and emotions has also been demonstrated, especially the neural connections between the somatosensory cortex and the emotional regions of the brain

such as the amygdala. This gives evidence for the strong connection between emotional awareness and tactile-bodily cognition. Emotions are easily carried in the tactile modality. The opportunities for bodily feedback during emotional reactions to influence tactile information processing by the brain are enormous. Thus, it is important to consider emotions as a powerful motivator for tactile learning.

A fundamental issue to address in any rehabilitation approach for individuals who have sensory deficits is the brain's ability to reorganize itself, called neuroplasticity or brain plasticity. Brain plasticity provides important clues for understanding the nature of sensory deficit and its relation to the brain. Are individuals who have sensory deficits able to compensate for their sensory handicap by developing exceptional abilities in their remaining senses? It is known that persons who have suffered major sensory loss, show compensatory, or even superior performance in the remaining senses. There is ample evidence for neuroplasticity that the brain reorganizes in people who are deaf or blind. Brain areas that serve specific functions for vision and hearing can take on a corresponding role for other senses in the reorganized brain in people who are deaf or blind. Such specific functions include the enhanced ability to detect visual movement in the deaf (Obleser, et al., 2006) and the enhanced ability to localize and identify sounds in the blind (Weeks, et al., 2000).

Recent brain imaging undertaken with people with acquired deafblindness shows a neuroplasticity associated with tactile language communication. A brain activation study of tactile language processing in a deaf-

blind subject showed that the tactile based communication activated the language systems and an extensive cortical network (Obretenova, et al., 2009). This means that tactile languages are equipped with the same expressive power that is inherent in spoken languages. It also suggests that the tactile modality is well equipped to handle communication and indeed language.

Likewise neuropsychological studies have shown that deafblind individuals perform significantly better than sighted-hearing people on tactile cognitive tasks. Studies demonstrate that deafblind individuals actually show superior performance on tactile memory recall tasks (Arnold & Heiron, 2002), and on tactile working memory tasks (Nicholas & Christensen, 2010) compared with sighted-hearing controls.

Recently, I had the opportunity to correspond with Sonia Margarita Villacres (S.M. Villacres, personal communication, July 19, 2011) from Ecuador, who lost her sight and vision at the age of 13. She wrote these wonderful words about the learning process involved to compensate for the loss of the visual and auditory functions to tactile functions: "The touch is a group of sensations not just in the hands, but also in the body. The skin is the touch sense that gives us more information. Initially the touch is "sleepy" you do not feel sensations or if you do feel you do not recognize them and it is not identified clearly in the brain. Now I can calculate the exact distance of the home furniture. I am able to plan in my mind the place of each one. By this I mean, that I am able to make an architectural drawing of the place when I know it by the touch, such as walking, touching the walls, etc."

As a tactile cognitive concept, Sonia Margarita is describing

the spatial reasoning through the tactile modality. This is a necessary function for forming a mental map of where things are. Visually, we use this kind of reasoning to organize our desks or remember where we left our keys.

Much of the research reported has been undertaken with people with acquired deafblindness, but if current thinking around neuroplasticity is correct then we should imagine that people with congenital deafblindness will have significantly increased abilities to perceive detail in the world through the tactile modality (Hart, 2010). This leads to the key question which is relevant for pediatric rehabilitation and for deafblind education: Has the child with dual sensory impairment or deafblindness significantly increased abilities to perceive detail in the world through the tactile modality than those whose senses are intact?"

- There is a paucity of evidence describing signs of neuroplastic functional changes following the combined and early loss of both vision and hearing in children. However, in exploring this question, it is important to state that children who are deafblind often use their own unique tactile communication signals, such as movements, muscle tension, postures, and gestures, which may be missed or misunderstood by parents or caregivers.
- This opens up the possibility that by making sense of these unique communication signals, by giving early exposure to tactile stimulation, through harmonious interactions and by creating/co-creating essential emotional relationships within the tactile medium we can help the brain of the deafblind child rewire itself.

Case illustration

By carefully observing or through

analyzing a video sequence of a child with deafblindness in a day-to-day communication situation or in every-day activities, we may be able to see the deafblind child perceiving the world in detail through the tactile modality.

This case illustration analyzes the video sequence of Emil exploring the hot lamp. By doing so it helps us to capture the different aspects of tactile information processing occurring in a natural setting.

Emil is from Denmark. In this video sequence he is about 5 years

“Recent brain imaging undertaken with people with acquired deafblindness show a neuroplasticity associated with tactile language communication”

old and we see Emil exploring a hot lamp in a natural setting. Emil has Rosenberg-Chutorian syndrome, which is an extremely rare genetic disorder characterized by the triad of hearing loss, degeneration of the optic nerve (optic atrophy) and neurological abnormalities, specifically peripheral neuropathy. Thus, he is a child with severe visual and hearing impairment. The video sequence (Emil and the hot lamp) is from one of the booklets on Communication and Congenital Deafblindness based on the work of Deafblind International's Communication Network (Rodbroe & Janssen, 2007).

So, what can Emil tell us about tactile information processing? Does this video sequence help us capture the different attributes

of tactile information processing, such as the aspects of tactile sensory functioning, tactile perceptual functioning, tactile -bodily learning, tactile attention & working memory, tactile memory, and tactile-bodily emotions?

The following is a description of the different attributes of Emil's tactile information processing system.

Tactile sensory functioning:

He reacts to a tactual object by regularly switching between seeking and distancing himself from the object. He felt pain, is still interested in the lamp, but now observing it from a safe distance.

Tactile perceptual functioning:

He recognises the object through touch and he explores and feels details of the object. He displays tactile perceptual behaviour which includes the discrimination of the tactile features of the object, tactile part-whole relationship and tactile-spatial perception.

Tactile – bodily learning: He is aware of how his body is related to the object, adjusts the position of the body to retrieve information and he can easily determine the location of the object (spatial reasoning). He is tactually learning by actively touching, tracing and finding the lamp. He displays anticipation during exploration.

Tactile attention or working memory:

He uses tactile-bodily information to modulate his attention focus in a flexible and graded manner, while sustaining his attention. He shows the ability to keep the relevant tactile information active over a short period of time, in an inner dialogue or inner “speech”.

Tactile memory: He describes the lamp by its tactile qualities from memory, has a tactile memory of

the painful event, and he recollects and localizes where it happened and how he reacted.

Tactile –bodily emotions: He expresses a gesture after he has processed tactually the thrilling and alarming event of burning his fingers. He perceives and recognizes gesture emerging from bodily emotional “traces”. These “traces” are referred as bodily, emotional and cognitive impressions that emerge as consequence of the tactile learning situation (Rodbroe & Janssen, 2007).

Even though in this video sequence we can observe the different aspects of Emil’s tactile information processing, it is important to emphasize Emil’s interaction with the competent communication partner during

this process. The competent partner is able to recognize, confirm, respond appropriately and interpret the tactile-bodily expressions of an emotional situation and together with Emil negotiate a shared meaning. This shared communication of the competent communication partner is an important and inseparable aspect of Emil’s tactile information processing.

Today Emil is about 15 years old and he has a cochlear implant. He uses his residual hearing in communication. According to Bettina Kastrup Pedersen, the consultant who is involved in supervising Emil and his network in Denmark, Emil still communicates a lot through the tactile medium. She explains that this may be mainly due to Emil’s parents enormous early intervention efforts of communicating with

him in the tactile modality (B.K Pedersen, personal communication, August 13, 2011).

This case illustration may suggest that in children with deafblindness, tactile perceptual abilities and underlying brain cognitive mechanisms can be modified as a result of increased tactual experience and shared communication within the tactile medium. Neuroplasticity is driven by what a deafblind child is learning and experiencing.

In conclusion, although a child with deafblindness may use residual vision and/or hearing for communication, active touch and body movements should be considered as an important or the main modality in any pediatric rehabilitation program that focuses on the needs of children with deafblindness.

References:

Arnold, P., & Heiron, K. (2002). Tactile memory of deafblind adults on four tasks. *Scandinavian Journal of Psychology*, 43, 73-79.

Donald, T. S. (2011). Functions of the Frontal Lobes: Relation to Executive Functions. *Journal of the International Neuropsychological Society*, Volume 17, issue 5, pp 759-765.

Engel de Abreu, P.M.S., Gathercole, S.M., & Martin, R. (2011). Disentangling the relationship between working memory and language: The roles of short-term storage and cognitive control. *Learning and Individual Differences*, Volume 21, Issue 5, pp 569-574.

Hart, P. (2010). Moving beyond the common touchpoint - discovering language with congenitally deafblind people. Doctoral thesis.

School of Psychology, University of Dundee.

Kostopoulos, P., Albanese, M. C., & Petrides, M. (2007). Ventrolateral prefrontal cortex and Tactile memory disambiguation in the human brain. *Proceedings of the National Academy of Sciences USA*, 104, 10223-10228.

Nicholas, J. (2010). From active touch to tactile communication - what’s tactile cognition got to do with it? *The Danish Resource Centre on Congenital Deafblindness*, issue nr. 12.

Obleser, J., Boecker, H., Drezanga, A., Haslinger, B., HenneLOTter, A., Roettinger, M., et al. (2006). Vowel sound extraction in anterior superior temporal cortex. *Human Brain Mapping*, 27, 562-571.

Obretenova, S., Halko, M.A., Plow, E.B., Pascual-Leone, A., & Lotfi B. Merabet, L.B. (2009). Neuroplasticity Associated with

Tactile Language Communication in a deafblind Subject. *Frontiers in Human Neuroscience*, 3, 60.

Rodbroe, I. & Janssen, M. (2007). Communication and Congenital Deafblindness. II: Contact and social interaction. *VCDBF, Denmark & Viataal, The Netherlands*.

Stuss, D.T. (2011). Functions of the Frontal Lobes: Relation to Executive Functions. *Journal of the International Neuropsychological Society*, 17, 759–765.

Wilson, M. & Fox, G. (2007). Working memory for language is not special: Evidence for an articulatory loop for novel stimuli *Psychonomic Bulletin & Review*, 14 (3), 470-473.

Weeks, R.A., Horwitz, B., Aziz-Sultan, A., Tian, B., Wessinger, C.M., & Cohen, L., et al., (2000). A PET study of auditory localization in the blind. *Journal of Neuroscience*. 20, 2664-2672.

Conference Plenary Presentation: Transition

Plenary Presentation, XV Dbl Conference, Sao Paulo, Brazil,
September 26-October 01, 2011



The title of this paper is a quote I heard in a movie sometime in the past year. I don't remember the title but it was something a mother said to her daughter as the daughter was trying to make an important choice about her life's direction. When I was asked to open the plenary on "Transition to Adult Life for Deafblind Young Adults", it was something that kept coming into my mind. I wanted to see how it would fit into this important topic. I think this is especially true for countries where professionals and parents are just beginning to connect education goals with post-school life.

In the United States, the term "transition" is a legal construct as part of our Education Law. It has been included in the law for almost twenty years and is followed by a set

of recommendations that mandate its practice as part of education for all children with disabilities. Here are some things that the law says about transition:

- Coordinated set of activities
- Results oriented process
- Facilitates child's movement from school to post-secondary education, vocational education, integrated employment, supported employment, adult education, adult services, independent living or community participation
- Based on child's strengths, preferences, interests

Further the law mandates that by age 16 a "transition statement" be included in each child's education plan and reviewed annually culminating in implementation when the young adult leaves school at age 21.

I was not able to determine how many countries in the world define transition in such formal and legal terms. I know in Latin America this is a relatively new term and I don't think yet defined in any country's education laws. We have some wonderful pioneers like Maria Graciela Laynes in Peru and Rocio Lopes of Costa Rica who have created model programs

and are helping to develop a Latin America model to transition.

In the United States we have had this law for almost twenty years and also a number of great projects that have developed specific programs for children and youth who are deafblind. A 2001 follow-up survey of 200 individuals who are deafblind, having transitioned from school found:

- 61% were living at home with families
- 82% were unemployed

For me this survey reveals two things: First that we have much more to do in creating successful outcomes for transitioning deafblind youth, and second, perhaps also we need to broaden our thinking about what actually is success.

For myself, when I first began teaching deafblind children thirty-three years ago, neither I or my co-teachers had ever heard the term "transition". We developed individual class and lesson plans and basically taught for the day trying to think of the next step; but never farther ahead than one year. In the next several years, transition or the future became more and more important. Most of our



Steve Perreault plenary presentation

students had been born during the Rubella epidemic of the 1960's and would be leaving school in a three year period beginning in the mid-eighties. Suddenly everyone began wondering about the relevance of what we were teaching and what it would mean in the future.

At that time though, we had no information about the adult life of deafblind individuals in the United States who were leaving school. Most of us had never met an adult who was deafblind and we couldn't picture a life that we could draw from to influence our planning or teaching. We could think a little bit about home skills; but work!! It seemed the only choices were between further education or sheltered workshops.

At the time our director, Mike Collins, reorganized our work and introduced new programs in vocational and independent living. As teachers began looking at possible job training sites they began to think about issues of communication and mobility. This led to more structured or sedentary job placements. This

led to my first real lesson about transition.

Jaimi was a student with reduced vision and hearing so that she had always communicated tactually. Yet she insisted that she wanted to learn a job involving people and not things. One creative teacher contacted a local hospital who agreed to a trial placement doing transport of mail and medical supplies in a large busy hospital. Many people thought this job would be impossible, yet Jaimi thrived because this was the kind of work she always wanted. She used her vision and mobility in ways no one had seen before. She developed adaptive communication strategies with co-workers. After her trial placement she was hired by the hospital and kept that job for ten years.

This taught me some important lessons:

- Transition is best when based on an individual's goals and preferences
- Learning and growth continue outside of the classroom
- Teaching and adaptations specific

to deafblindness are essential.

- Never limit expectations

In 1986 in our state of Massachusetts, a coalition of parents and professionals worked very hard to secure funding to support the transition needs of the large group of deafblind young people transitioning over the next few years. The funding supported a program of adult services within our rehabilitation system. At this time I was hired to direct the program so as seventy deafblind individuals transitioned from school to adult services, I transitioned from a job as a teacher to managing this new adult services program. Over the next few years our department developed apartments, group homes and other living options. We expanded day programs and supported employment. For the most part we worked with agencies that had never worked previously with a deafblind person. Since this was one of the first services of the kind in the United States, I was often asked to travel

to other states to talk about our work. I shared some important points that I had learned while creating programs:

- Planning must be individual and person-centered
- There needs to be an entry point into services so individuals are not sent from department to department
- Communication and Mobility access is essential to making services accessible
- Programs often require additional people to provide the hands that make services accessible
- Training and technical assistance must be readily available to support opening doors to new programs
- Multiple collaborations are important to meet the diverse needs of this population
- Teaming with family members and care givers must be part of planning.

Of course I had much more to learn. However as we came to the end of our funding, I had few placement options. I was excited when I found a placement in a home for one of the last transitioning individuals of that time. I told the mom, "This is a wonderful home, the staff is very well trained and they use total communication. They have wonderful recreation programs in the community. Go visit and tell me what you think." The next day she called and simply said "NO!" I was shocked and asked "Why?" She said, "I always pictured my son living in a home with a tree in the backyard." We eventually compromised but this led me to think that there was more we should be doing to form a more inclusive and equal partnership with families. Sometimes what professionals think is important may be different from what

“Most of us had never met an adult who was deafblind and we couldn’t picture a life that we could draw from to influence our planning or teaching”

families think.

In 2007 the National Family Association for Deafblind in the United States contacted 500 families and received 150 responses as to what is most important in planning for their child’s future. Here is what parents said:

- 90% identified physical and emotional safety and quality of life as most important.
- 70% included financial security
- 64% said life-long learning
- 62% said a place to live
- 60% said good relationships with their adult brothers and sisters

For parents the worry is, "What will life be like for my son/daughter after I am gone?" From this experience and from meeting and working with hundreds of families across many countries I have found a great commonality in the concern parents have for the future. For us as educators I think we need to:

- Plan for real lives and not to meet regulations
- Be flexible and offer choices
- Use maps or other planning tools for common language
- Include parents/families/ caregivers in all parts of planning
- Plan for each individual and family

From the lessons I have learned I would offer the following as defining transition as a place to begin where there are laws or no laws, services or minimal

services and as a guide to how we think about planning education programs that will offer value to students who are deafblind now and into the future:

- Transition is a lifelong process
- Transition is the discovery and growth of passions, preferences and abilities
- Transition is collaboration with parents, families and caregivers
- Transition is connection to community and opportunities
- Transition assumes that learning continues at all ages

I return to the phrase "Being loved is important Being Loving is Essential" which to me provides a focus on educators as the facilitators of connecting each child or young person who is deafblind to discovering and expressing all that is joyful and life affirming. I hope I would have an ally in Paulo Friere when he wrote:

"What is important in teaching is not the mechanical repetition of this or that gesture but a comprehension of the value of sentiments, emotions and desires. Of the insecurity that can only be overcome by inspiring confidence. Of the fear that can only be abated to the degree that courage takes its place"

And: "Unfinishedness is essential to our human condition."

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8th DbI European Conference

Identities and changes

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Transition and a family's experience from Kenya

I am Joseph Shiroko from Nairobi Kenya. I am the father of 24 year old Brian, born deafblind from German measles. I have been involved in parents/families activities since the early 1990s. For more than 14 years I have served in transition initiatives for the Deafblind in Kenya. I am widely traveled and have made presentations at several functions worldwide in the general area of disabilities. I consider myself a major player on the disability landscape in Kenya with a vast experience of Disability and Community Development Consultancy work. I serve at the Brian Resource Centre in Nairobi as a Programme Coordinator. I am also a board member on the National Council for Persons with Disabilities in Kenya for the period 2011-2013.

Why is this topic important?

Transition still remains a big challenge to those of us involved in my country. The concept is not well understood in Kenya; and those who are practicing it do it on the basis of how we know best or want to do it. Team work and coordination is largely lacking. There is weak preparation on the part of the parties involved. The end result is that a lot of otherwise good gains are lost, resulting in setbacks for deafblind persons and their families.

Personal Experiences:

The journey of raising Brian and taking him through the life stages has had many ups and downs through many transitions. As a family, we have suffered stigma and isolation as well as ridicule. It was very difficult to have

Brian interact with other children. Many families shunned us because Brian was not well understood and received by those around him. His hyperactivity only made things worse.

Getting the appropriate school was very difficult; we did not know where to begin. We went to the nearest schools and moved from one to another as the situation dictated.

Meeting Penny Kamau and Joseph Morrissey (then working for the FSDB/SHIA project and CBM respectively) was one of the best things that ever happened to our family. Eventually, Brian got assessed for education and



Joseph Shiroko





Brian Resource Centre Graduation Ceremonies

was placed in a schooling program.

The journey through the schooling programme was very bumpy. Interacting with other service providers when all of us were on a learning mission had its own challenges.

Working on capacity building and joining Parents and Family Support Groups was one of the best things that happened to us. We grew in stature and eventually started our own school with big dreams.

Along the way, I changed my career, turning into a service provider. I have since worked with FSDB/SHIA on a

transition program targeting deafblind persons in Kenya. At the end of the FSDB/SHIA Program in Kenya, I created the Brian Resource Centre for Deafblind persons and families in Nairobi. I serve as a Program Coordinator. We appeal for every support to enable us to construct appropriate facilities.

At the centre we train deafblind young adults and their families on practical and sustainable family and community life skills. We are also involved in lobbying, advocacy and awareness creation. We also work in great networks targeting the improvement of the quality of life for deafblind persons and their families.

Our Gratitude and the way forward:

Many players here have been of great assistance to us, including: FSDB/SHIA,

Parents of the Deafblind from Sweden, CBM, Hilton Perkins Programme, Sense International, Parents Movement in Kenya, the Disability Fraternity in Kenya, and The National Council for Persons with Disabilities.

We face the future with courage and optimism. We trust that the program will grow in strength and more lives of deafblind persons and their families will be touched.

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“Many families shunned us because Brian was not well understood and received by those around him”

Letting go: Transition into adulthood

A Scottish parent

Marshall my son was born following my contracting maternal rubella. He was born with severe hearing loss and bilateral cataracts so he was totally blind at birth. The rubella continued to damage his hearing until he was about three years old resulting in a profound hearing loss. But through several operations on his eyes, the cataracts finally receded giving him extremely useful vision. When he was growing up we used personal signs, photos, objects of reference and really any kind of communication that worked.

Now at 36 he uses British sign language (BSL) in both English and Scottish signs. I have no idea when this happened; it just emerged over time. Communications now can be really good, but between us as parents and Marshall, it can still be limited. I think this might be because he is least interested in what we have to say. When his sister or younger deaf friends come he communicates brilliantly. This is perhaps not about understanding but rather about motivation and interest. It is probably less to do with being disabled and much more about being bored around older parents.

Letting go didn't come in one big move. For us it didn't happen like that; yes he moved out of the family home but there was no letting go. There were constant meetings, visits, phone calls. We were not letting go; Marshall was not sure – he was confused, angry and emotional. I'd like to say the process of crossing this imaginary line between child and

adult only took a few years; but looking back it has probably taken ten years or more.

If we think about our able bodied children leaving home, they still come back; we do their washing, we give them money, we still make anxious phone calls and I have occasionally even been known to quietly check what they are eating by having a quick look in the fridge! And despite both my children being in their 30's I have never let go and I don't suppose I ever will.

I remember many evenings with Norman Brown, talking about our boys - what Stevie and Marshall were doing now; how they were growing up and us worrying about their latest behaviours. I remember Norman saying to me that as parents we are the ones who understand our children best; we



“I'd like to say the process of crossing this imaginary line between child and adult only took a few years; but looking back it has probably taken ten years or more”

take a million 'snapshots' of their behaviour every day. Norman said that any psychologist could never get that level of knowledge and understanding; Norman was right.

Still what that closeness brings is that we learn to anticipate what our children need. When our children are young that's brilliant; it's a great learning tool, a 'reinforcer' which helps a child to build up learning and confidence. However as our children get older is it possible that these deep bonds begin to disempower our children? Instead of making the young adult 'work' at communication, we anticipate for them. Perhaps, through this anticipation our children's need to communicate is reduced.

The term transition makes it sound that it's a line that's crossed, when we reach a certain age. In the UK from about the age of 14 we start to 'future' plan. This is purely chronological, based on the move from education to social care services; it has absolutely nothing

to do with a child's actual level of maturity.

As parents we have to work within these boundaries and definitions only because the structures that support our children require it. So that's what happened. Around the age of 16, Marshall left school and entered the world of social services. There were, of course, many different social workers all with their different and often 'ill informed' opinions.

It was really only in Marshall's early 30's that things began to settle down for him. Looking back I think this was less to do with us as parents or the different placements; it was much more to do with Marshall himself. He began to mature; I'm not sure I

realised it while it was happening - he just seemed to get there.

It was the little things, such as: buying his own presents at Christmas; helping his grandmother while out walking; keeping his own wallet and money; very definitely choosing his own clothes, and developing his own style. Bit by bit Marshall made his own transition and we gradually learnt to trust and finally begin to let go. This is as much as any parent can do for any child.

Now Marshall lives in his own house with Sense Scotland staff supporting him on a 24 hr basis. Marshall's move to his own personal space further enhanced his independence.

What I have learned is that

transition is just a professional term for growing up. Each of our children will do it in their own way; only when they are ready.

Looking back and being genuinely reflective, as parents I'm sure we caused distress; I am sure contributing to challenging behaviour. I can punish myself or I can say - we did the best we possibly could. Now, as I look at a mostly happy almost middle aged man, who ignores his parents because that's who we are, then I understand that he has made his own life in spite of us. Actually despite the ups and downs, perhaps we didn't do such a bad job and Marshall did an even better one.

Gill Morbey

A Brazilian parent's difficult journey

The journey as a parent of a daughter with deafblindness has been difficult.

It is difficult in Latin America to find services to support the needs of the families.

These needs have led us to work together with professionals to study the issues of deafblindness. If parents are not prepared to work together we won't achieve anything.

There are many differences among our children with these disabilities, all with different abilities and capabilities. This means we must develop skills as parents to enable us to guide our children to achieve their possibilities. As a parent, if I had known more I would have been able to do more for my child.

I had come to realize that for our children, "transition" is forever. With respect to our deafblind adult

children, the question is "what can we do?" Who will take care of them when we are aged? These are not easy questions. Currently in Brazil there are no programs to help our older children.

For me, our family lives in a northern state of Brazil. Without adult services outside the home, we have to organize our family home accordingly to meet the long term needs of our adult child. Since there is no other independent facility for our child, we must be prepared to meet her needs into the foreseeable future.

This is all very difficult for families all over Brazil. We have to deal with the health issues of our older children as we become older ourselves.

At the same time, as part of



Grupo Brasil, we are working towards a future solution to this dilemma.

Currently our focus is on the education of young children. The better education we provide these children the better the transition will be for them as they become adults.

Susana Araoz

Editor's message continued from page 3

a lifetime of opportunities' that one can read through in this edition; one from Israel and the other from Canada. Adina Tal's article about the theatre group, Nalag'at, describes a special initiative in Israel that helps sensory impaired people work, earn a living, achieve self-fulfillment and nurture their unique abilities and talents. Jane Sayer describes a program in Manitoba, Canada which provides deafblind people with Intervenor services. In the article, Jane outlines her personal situation, providing another good example of 'inclusion for a lifetime of opportunities'.

Second, it was very pleasing to hear more presentations of scientific articles having reference to deafblindness. The growth of the science in deafblindness is a tremendous gift for those working with deafblind individuals; it provides professionals, Intervenor, family members and deafblind people themselves, a better understanding of brain interconnections with individuals with multi sensory losses. One example was Dr. van Dijk's continued influential work in assessment of congenital deafblind children. His work, explained at several sessions during the conference and in more detail at the Pre-Conference, reveals the importance of the brain's limbic system and mirroring system for establishing

an emotional connection (considered a precursor to communication) between these children and their care givers.

Another great example is Jude Nicholas' work on the tactile sense, where he presents, among other things, research that connects deafblind persons tactile memory to developing an understanding of language.

This discussion so far about science and inclusion, would not be complete without recognizing an article in this magazine

“It is a privilege to witness the impact that family members continue to have in the field of deafblindness”

about deafblindness and dialogicality. The article from Rafaël School in the Netherlands outlines research studies by three teachers, one of whom describes her work in a workshop at the Brazil conference. I bring this up to connect the growth of science (in this case, developmental psychology) impacting on improved communication development; the end result, of course, being better inclusion!

Finally, it is a privilege to witness the impact that family members continue to have in the field of deafblindness. Take the fact that the CEO of a major international deafblind

organization (Sense UK) is a parent of a deafblind person. That person, Gill Morbey, I am proud to say is now the President of Dbl. Other notable parents or family members, in addition to Gill, who had prominent roles during the conference included Joseph Shiroko from Kenya who spoke about starting their own organization to serve children, like his son Brian; Susana Aroaz, from Brazil, President of the local planning committee of the XV Dbl Conference, member

of the scientific committee and an organizer of the Families Pre-Conference; Marcia Souza, prominent member of the planning committee and the Family pre-Conference, as well as a plenary and workshop presenter, etc. I can't forget, Dr. Isabel Amaral, Chair of the Scientific Committee, herself a sibling of a deafblind man from Portugal.

Finally, thanks to the many contributors for your material to this edition; and for your patience with me! I trust you will enjoy this edition. Your comments and articles are welcome.

Stan Munroe

Plenary Session: UN Convention – Rights of Persons with Disabilities, October 1, 2011

Plenary Presentaion: Lex Grandia, President World Federation of the Deafblind

Thank you for inviting me to speak about the Convention on the Rights of Persons with Disabilities, the CRPD. The CRPD is a legal document, an international law, that was formulated during the negotiations in the United Nations between all the 192 member states of the UN. The international disability organisations have been involved and I have been there to try to put deafblindness in the document as good as I could.

This happened between 2002 and 2006, so now the document is almost five years old. At this moment 149 states have signed the CRPD. That means that they in principle agree with the text. Of these, 103 states have ratified, which means that these states are trying to make all the rules, the legal measures in this convention into national legislation. That means that many national laws which involve persons with deafblindness need to be changed. It is here where we, persons with deafblindness and persons working with deafblindness, need to be alert. We are a small group. We are easily forgotten in the national procedures established to implement the Convention. If we are not included in these procedures, the human rights of persons with deafblindness will not be implemented in accordance with the Convention.

This convention is about all areas of life: families, education, legal capacity, dignity of the person, privacy, non-discrimination,

social security, access to health and rehabilitation, accessibility, accessible information, employment, culture, political participation, awareness raising and statistics.

How can we make it work for persons with deafblindness of all ages, their families and professionals? We need to influence our governments and local authorities, so that we get legislation according to the rights enshrined in the CRPD.

The first thing we have to do is to raise awareness. We need to describe what the barriers are for persons with deafblindness to participate in the community just as everybody else. We need to publish the stories of persons with deafblindness; describe the consequences of the dual sensory impairments and the many different ways in which persons with deafblindness try to cope with their situation.

We need to make a clear plan of what we want to fight for in the negotiations with authorities. We need to make priorities: what is the most important, what comes first, what can be done now and what has to grow in the process.

We cannot do it all alone, so we have to make alliances with for instance our blind and deaf friends and those who are advocating for their rights. We have common areas, for instance: Braille or Sign Language, technical aids and information technology. Also persons with intellectual disabilities or psychosocial disabilities can have

many issues in common with what we are fighting for, for instance involuntary institutionalisation, the right to vote and have legal capacity. Also here, among different disability groups, the raising of awareness is very important, with the opportunity to exchange experiences.

We have to realise, that we work on all kinds of areas and might need to go to different ministries or committees - not only social affairs, but also employment or education, but we should do that together with other disability groups to get a stronger voice.

Of course, this legal convention is a dream; it is an agreement where many rules can be implemented with not so many financial consequences. We need to find creative solutions and help politicians (who do not know anything about living with a disability) to remove barriers that most of us with deafblindness, experience. But once we start, we are more creative than we thought. Things have to be done step by step; we need to make priorities: what comes first and what can wait a bit longer. But if we do not do it now, we will be forgotten.

States have to report to the CRPD committee in Geneva how far they are with their implementation of the CRPD. States always try to make the best pictures of what politicians have tried to accomplish in national legislation; but we know better. Therefore in many countries disability organisations and professionals, also family



**Lex Grandia
presentation on
UN Convention**

organisations, are writing parallel or shadow reports to the CRPD Committee in Geneva.

The World Disability Report

There is another very important document produced by the World Health Organisation and the World Bank that was launched on June 9 this year called 'The World Disability Report'. I have been involved in making this 700 page report accessible in alternative formats.

The report indicated in its conclusion that the CRPD established an agenda for change.

There is a reference in this report to deafblindness; but not much, because we are a small group.

The report gives a lot of interesting information. It tries to be as scientific as possible. I do not always agree with the rather medical approach and some conclusions are far too weak.

This World Report on Disability documents the current situation for people with disabilities. It highlights gaps in knowledge and stresses the need for further research and policy development. It presents a list of recommendations that can contribute towards establishing an inclusive and enabling society in

which people with disabilities can flourish.

What do we know about disability?

More than a billion people are estimated to live with some form of disability, or about 15% of the world's population (based on 2010 global population estimates).

The number of people with disabilities is growing. This is because populations are ageing – older people have a higher risk of disability – and because of the global increase in chronic health conditions associated with disability, such as diabetes, and other conditions.

What barriers did the report find?

Inadequate policies and standards, negative attitudes, problems with service delivery, inadequate funding, lack of accessibility, lack of consultation and involvement, lack of data and evidence.

What are the effects on the lives of persons with disabilities?

Poorer health outcomes, lower educational achievements, less education, less results also in

higher income countries, less economic participation, poverty in all countries, less independency and less participation, reliance on institutional solutions, lack of community living and inadequate services leave people with disabilities isolated and dependent on others, most support comes from family members and those families become more vulnerable because of stress and less possibilities of more economic development of the family.

Residential institutions are reported to be responsible for a lack of autonomy, segregation of people with disabilities from the wider community, and other human rights violations.

Recommendations from this report:

- 1: enable access to all mainstream systems and services
- 2: invest in specific programmes and services for people with disabilities
- 3: adopt a national disability strategy and plan of action
- 4: involve people with disabilities
- 5: improve human resource capacity
- 6: provide adequate funding and improve affordability

- 7: increase public awareness and understanding
- 8: improve disability data collection
- 9: strengthen and support research on disability

So, what can we do?

Disabled people's organizations can:

- Support people with disabilities to become aware of their rights, to live independently, and to develop their skills.
- Support children with disabilities and their families to ensure inclusion in education.
- Represent the views of their constituency to international, national, and local decision-makers and service providers, and advocate for their rights.
- Contribute to the evaluation and monitoring of services, and collaborate with researchers to support applied research that can contribute to service development.
- Promote public awareness and understanding about the rights of persons with disabilities – for example, through campaigning and disability-equality training.
- Conduct audits of environments, transport, and other systems and services to promote barrier removal.

Service providers can:

- Carry out access audits, in partnership with local disability groups, to identify physical and information barriers that may exclude persons with disabilities.
- Ensure that staff are adequately trained in disability, implementing training as required and including service users in developing and delivering training.
- Develop individual service plans in consultation with disabled people, and their families where necessary.

- Introduce case management, referral systems, and electronic record-keeping to coordinate and integrate service provision.
- Ensure that people with disabilities are informed of their rights and the mechanisms for complaints.

Academic institutions can:

- Remove barriers to the recruitment and participation of students and staff with disabilities.
- Ensure that professional training courses include adequate information about disability, based on human rights principles.
- Conduct research on the lives of persons with disabilities and on disabling barriers, in consultation with disabled people's organizations.

Communities can:

- Challenge and improve their own beliefs and attitudes.
- Promote the inclusion and participation of disabled people in their community.
- Ensure that community environments are accessible for people with disabilities, including schools, recreational areas, and cultural facilities.
- Challenge violence against and bullying of people with disabilities.

People with disabilities and their families can:

- Support other people with disabilities through peer support, training, information, and advice.
- Promote the rights of persons with disabilities within their local communities.
- Become involved in awareness-raising and social marketing campaigns.

- Participate in forums (international, national, local) to determine priorities for change, to influence policy, and to shape service delivery.
- Participate in research projects.

So, this is the legal and the practical work that is ahead of us. I hope you will understand, that now is the time to act, because now we are on the political agenda. I know, there is a financial crisis going on, but we are not just asking for money. We ask for legal and political acceptance and together we will solve the financial problems.

Nothing about us without us!

Lex Grandia

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More about the UN Convention – Rights of Persons with Disabilities

- The CRPD (Convention on the Rights of persons with Disabilities) text can be found in PDF version in 6 UN official languages and 18 national translations including Hungarian and New Zealand sign language version, audio version and easy to read versions. <http://www.un.org/disabilities/deafult.asp?id=150>
- Countries who have ratified CRPD and a short presentation of CRPD in English <http://www.un.org/disabilities/>
- To get the CRPD text in your national language, including your national sign language and in Braille contact the ministry in your country responsible for the translation.
- World Report on Disability Published by WHO and The World Bank, June 2011 Download full report from http://www.who.int/disabilities/world_

report/2011/en/index.html

Available in Daisy, Easy to Read and Accessible PDF in English. A summary is available in accessible PDF and Daisy format in the 6 UN languages. Print version from WHO Press, World Health Organisation, 20 Avenue Appia, 1211 Geneva 27, Switzerland

tel +41 22 791 3264

- Guidance document on parallel reporting on national report to the CRPD Committee In English, French, Spanish, Arabic. <http://www.internationaldisabilityalliance.org/projects-and-events/guidance-document-on-parallel-reporting/>

org/projects-and-events/guidance-document-on-parallel-reporting/

- CRPD Committee <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx>
- CRPD and Deafblindness contact Lex Grandia lex.grandia@mail.dk or wfdb@wfdb.org

Respondents to Plenary

Antonio Ferreira

I bring you regards from our President Dilma Rousseff. First I must tell you that the Convention is a great document for Brazil. In Brazil we have had the legislation prior to the convention; now this convention provides more support for the government of Brazil to guarantee the items written in its own constitution.

Disabled people here in Brazil are challenged every day; especially among the many poor people. Myself, as a blind person, was a good example of this as I came from a poor family in the state of Pernambuco and was unable to attend school until the age of 12 years.

What advancements have we had in Brazil to assist people with disabilities? The list includes better accessibility in modern architecture; sign language on TV (for 2 hours per day); a guarantee of support for people with intellectual disabilities. These supports include a wide range of resources, materials, teacher training, strategies, etc.

I have worked hard in government to make politicians aware that new policies are necessary to take into account the needs of disabled people. We need to continue to work continuously to improve the awareness.

In my mind there have been some good results for which I am positive. However, we should all



Antonio Ferreira (left) and Dr Ricardo Tadeu

understand that improvements for disabled people will only come with pressure from disabled people themselves. These are our rights!

Mr Ferreira is the National Secretary of the Secretary of the Rights of Persons with Disabilities of the Brazilian Ministry of Justice
Dr. Ricardo Tadeu

This UN Convention can be described as the most democratic of the UN conventions. Many individuals with disabilities had an active voice in the process of developing this document. It can be called a true revolution in the field of human rights. This revolution proposes a legal change in the definition of people with disabilities; it moves beyond a clinical definition towards the acceptance of their social reality.

People with disabilities deal with many barriers that make it difficult for them to access their human rights. Section 3, in a sense declares that disabled people are full participating citizens in

the world, having equality of opportunity, without further discrimination, being respected for their difference including gender equality, etc.

People with disabilities are now recognized as traits similar to gender or race. Thus we're now seen as full citizens.

Section 4 of the convention sets our obligations by the member states 'to take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes'.

Some people say that the current economical situation makes it more difficult for the states to implement these rights. That is not the case! It is fundamental that demands are made on governments to protect the rights of people with disabilities. It is time now for states to accept their responsibilities.
Dr. Tadeu is a Federal Prosecutor in the Brazilian Ministry of Justice. He is the first person with a disability to hold this position.



Inclusion for a lifetime of opportunities

XV INTERNATIONAL WORLD CONFERENCE

Sao Paulo Brazil, September 26-October 1, 2011

Reflections from a local committee member

Generally Speaking

The theme of the conference, 'Inclusion for a lifetime of opportunities' was the guiding spirit practiced throughout the entire conference. This meant, for example that all participants should have equal opportunities to attend or take part in any activity of the conference; all that is needed is the will to do it!

The conference brought together about 340 people representing 35 countries, consequently including many cultures from around the world. All plenary sessions were translated verbally and through sign, into 3 languages: English, Portuguese and Spanish. Although the official language was English, the local and the scientific committees worked hard

so everybody was included despite their language requirement. This was a special advantage for Latin American participants and those from Spanish and Portuguese speaking countries. This meant that the workshops and posters could be presented in the person's native language, with many volunteers doing their best to translate at the workshops, poster sessions, networks and special sessions.

The organizers counted on our tireless volunteers, many who were sign language interpreters both for the deaf and for the deafblind. They worked with great excellence and professionalism to make it possible for Brazilian deafblind people to fully participate in the conference, exchange experiences among themselves and with



deafblind and other participants from other countries.

In Brazil we value what the plenary speakers had to say, which led to some time delays. I am sure the participants did not mind having such a tight schedule for lunch as they were nourished by the delicious program our scientific committee put together. The plenary topics featured a smorgasbord of relevant and diverse topics in the field that included "Inclusive Education, Pediatric Rehabilitation, Neurological and Cortical Etiologies, Assistive Technology, Transition to Adult Life and the UN Convention on the Rights of People with Disabilities. The speakers were specially selected for their expertise and addressed the topics with mastery. We detected great approval among the participants for the plenary presentations.



The Formal Opening Night

During the opening night of the Conference, representatives from several Brazilian authorities (Ministry of Education, Secretary for the Rights of the Persons with Disability from the State of Sao Paulo and the Secretary for the Rights of the Person with Disability and Reduced Mobility from the City of São Paulo) showed that they believe and are willing to invest in the cause of deafblindness in our country. We were pleased to hear them praise the successes of Co-Chairs Shirley Maia and Nina Cormedi who represented successful Brazilian deafblind programs developed in Brazil.

After all the speeches we had a pleasant surprise that brought to life the meaning of inclusion for a lifetime of opportunities: the blind ballet dancers dancing classical pieces on point, jazz and in duets. Their grace and lightness suggested there are truly no limits for anyone. Everyone in the crowded auditorium was on their feet, marveled by the hypnotizing movements of the beautiful dancers filling the place with a shared feeling of joy and awe.

The rest of the week

The first day of the conference started with a keynote describing the programs developed in Brazil. This was followed by a very positive report from Pan American Health Organization about the state of rubella and congenital rubella syndrome in Latin America.

Apart from six plenary sessions, more than 90 workshops and almost 90 poster sessions, several special sessions (a presentation of Brazilian scientific and academic research activities; two sessions by Dr. Jan van Dijk's - one on the limbic system, another on assessments) and network meetings made up the four day conference.

The hectic week at the



conference provided additional opportunities for cultural exchanges. This included the Opening Night cocktail session (featuring the famous caipirinha), samba night that some people experienced at the Jockey club, the sailing adventure at the Paulista Yacht Club enjoyed by some deafblind people, tourist day that many people enjoyed with private and organized tours to the coast or tours of the city, and finally the gala dinner special evening.

The gala dinner event gave an opportunity for Dbl and Perkins International to hand out its special awards. There was a Dbl Lifetime achievement award handed out to Mari Saetre from Norway who was unable to attend. Dbl Distinguished Service awards were received by Lex Grandia (Denmark), Bernadette Kappen (USA) and our own Shirley Maia from Sao Paulo Brazil! The coveted Ann Sullivan award was presented to Isabel Amaral (Conference Scientific Committee Chair from Portugal) and to Co-Conference Chairs Maria Aparecida Cormedi and Shirley Maia. This was the second time in the history of a Dbl Conference that a person (Shirley Maia) received both the Dbl and

Perkins awards. Congratulations Shirley! Congratulations to all award winners; you certainly deserved to be acknowledged for all your work, dedication and contributions to the field of deafblindness.

Closing the conference

The last plenary session addressed the UN Convention on the Rights of Disabled People. This was followed by the words from the new Dbl President Gill Morbey.

The grand finale came with a presentation by deafblind ladies and friends dancing as ancient Greek women symbolizing the frailty and beauty of women. This was choreographed based on the works of Isadora Duncan whose depiction of Greek dancers was inspired by classical Greek sculptures and other works of antiquity. This finale was but a final example of the inclusion theme of the conference - that no advanced age or disability can limit the human being who is full of possibilities.

We miss you all and hope to see you soon perhaps at another Dbl conference.

Vula Maria Ikonomidis

Brazilian organizers have much to be proud of!



Conference Official Opening Session

It has been common practise that the planning time to organize a Dbl World or Regional Conference would take close to four years, from the initial time of being awarded the conference to the starting date of the event. Usually during the first two years, there is a little 'breathing time' for committees to be formed; organizers to consider a range of local venues, organize fund raising, liaise closely with Dbl to ensure the theme and the committee structures are approved, start the conference awareness process, create a website, etc. However, the Brazilian organizers for the XV Dbl World Conference did not have the luxury of this typical conference planning time of four years.

Due to unforeseen circumstances the original organization awarded the conference was unable to continue and Dbl immediately appealed for another country that could possibly host the 2011

conference within a now very short two year time frame. Grupo Brasil, the organization that had previously applied to host the XV Dbl Conference, expressed their willingness to host the next conference, with confidence they could do it within the two year timeframe. At the European Conference in Senigallia, Italy, September 2009, the bid from Brazil to host the conference in 2011 was accepted. Personally, I



felt confident that the Brazilian organizers could "pull this event off" and that it would be a memorable one! I had been in attendance at 3 Brazilian national conferences (2004, 2007 and 2010) and knew of their ability to stage high class conferences. I was subsequently appointed to be the Dbl contact person with the Brazil organizers, eventually becoming a member of the local planning committee.

The first meeting of the local planning committee, which consisted of representatives of Grupo Brasil and AdeFav, was held in early December 2009. From this point on, planning went into high gear. In a very short time the following details were put into place: a scientific committee was recommended and ultimately approved by Dbl; the venue, Bourbon Ibirapuera Convention Center and Hotel, located in the Moema region of Sao Paulo city was selected; Acquaviva Promoções

e Eventos was appointed as conference managers responsible for all conference logistics; Ximena Serpa was hired as the Conference Secretary.

The local planning committee met on a regular basis through the remainder of the short planning period. The scientific committee made up of members from Argentina, Brazil, Ecuador, Portugal, UK, Norway and USA, met in Sao Paulo in February 2010 to develop the theme and the Call for Papers process. They met again in February 2011 to formulate their excellent program.

The rest is history.

The attendance of approximately 340 was a little lower than was hoped for. Some of the organizations which normally send large delegations to these conferences, limited their participation this year due to their economic circumstances. This was partly offset by the



large increase in attendance from the Latin American countries, which represented one third of the countries participating and half of all attendees. Having the conference in Brazil was of great benefit to Latin American people as it allowed for many professionals, deafblind people and many family members to participate. This is only the second time that a Dbl conference has been held in Latin America, the first since 1994, when Cordoba

Argentina was the host city.

The opportunity for members of the international community to learn and network together in a wonderful atmosphere, topped off with memorable social and cultural opportunities can never be understated.

My congratulations to the co-hosts, Grupo Brasil and ADEFAV, for an incredible job well done!

Stan Munroe
Dbl Information Officer



Cameo glimpses of people and events during the Dbl XV Conference, Sao Paulo, Brazil, September 26-October 1, 2011

Photographs contributed by Lasse Winther Wehner, Benedito de Oliveira and Stan Munroe





Deafblind Sailors

Another example of 'Inclusion for a lifetime of opportunities'



Miguel Olio

During the tourism day (September 30th, 2011) of the XV World Deafblind International Conference, the Paulista Sailing Group from the Paulista Yacht Club, myself physical educator Miguel Olio and Grupo Brasil Program "S" Day organized a sailing experience for ten deafblind people who were attending the Conference. Program "S" Day is Program "Surdocego" Day or Program for the Deafblind Day in Portuguese. This is a program sponsored by Grupo Brasil where supporters provide financial support for intervenors, transportation and facilities to provide cultural, leisure and sports activities for people with deafblindness.

Deafblind people from Portugal, Sweden and those from a number of Brazilian cities (Manaus, Angra dos Reis, Campo Grande, São Paulo, Curitiba, Florianópolis and Bauru) participated in this sailing event. The deafblind participants were assisted by guide interpreters from Grupo Brasil and Ahimsa, an Educational Facility for deafblind and multiply impaired people in São Paulo.

Preparations

Prior to sailing day, several test sails were done with two deafblind individuals to get their feedback to determine



the practicality of staging this event.

On sailing day, preparations started early in the morning so that everything would be ready when the participants arrived. We brought the sailing equipment to the water, organized the life vests for everyone to wear, determined the sailing route and sequencing for each of the boat trips, organized which individuals and intervenors were sailing together and planned other events for the day.

Prior to sailing, instructions were given to all the participants, including the intervenors, how and when to hoist and lower the sail, how and when we needed to change positions in the boat when tacking and how to steer the boat.

For the sailing excursions we used a 7 meter keel Ranger 22 along with a 3.8 meter dinghy equipped with a 15hp engine for emergency

purposes. On each trip there included myself and two deafblind individuals, each with their own intervenor. Each participant was provided the same opportunity; the information was transmitted by the intervenor and each one had their own time to receive and process the information during the sailing.

Impressions of the participants following the sailing event

After the sailing event, each participant was interviewed about their experience. They were asked to comment, for example, whether they noticed the influence on boat speed with lowering or hoisting the sail; could they notice large and small shifts in direction of the boat? Did they have problems maintaining their balance during directional changes of the boat, etc. They were also

asked what they liked best - did they like to do the sailing procedures independently? Or did they prefer working with the sails as a team? Or was steering the boat their preference? Most importantly, they were asked if they had fun!

The follow-up interviews indicated that each participant had their own preferences in sailing. Some indicated they preferred to sail the boat alone. Others enjoyed helping with the mainsail or with the genoa (jib) sail; while others simply enjoyed the movement of the boat and experiencing the changes in boat speed and direction. There were even some of the sailors who took the boat back to the yacht club on their own... with the intervenor at their side, of course.

Conclusions

The aim of this event was to further promote social and sport inclusion of people with deafblindness. The intention was also for them to show their own possibilities and capabilities in such activities. The results showed different personal styles of sailing: some sailors showed they could sail with minimal assistance from an intervenor (directional guidance), while other individuals showed they could sail as a team with one person managing the main



sail, another steering the boat, etc. Their individual style depended largely on their level of confidence and whether they wanted to sail alone or be part of a team.

This sailing experience further demonstrates how important it is to provide as many opportunities for these individuals as conceivable; to help break their isolation from the rest of world. The success of this project demonstrated that it is very possible for deafblind persons to participate in this sport, with minimal assistance or support. In the near future, it is quite conceivable that deafblind people may be participating in sailing competitions.

Miguel Olio
Physical Educator at Ahimsa
and sailing instructor

“The aim of this event was to further promote social and sport inclusion of people with deafblindness”

14th European Rehabilitation and Culture Week for Deafblind people

Castberggård, Denmark
August 13th - 19th 2012



Focus on Deafblindness and Dialogicality in the Netherlands

This presentation describes how we, at Kentalis Rafaël, a school for children with deafblindness in the Netherlands, transfer to practice the theoretical knowledge about dialogicality.

Kentalis

Kentalis is a national organization in the Netherlands that provides diagnostic, family care, day care, early intervention, rehabilitation, case management and educational services to people for whom the ability to hear or communicate is not a natural one. We offer services for people that are deaf or hard of hearing, people with specific language impairments, people with autism or other mental impairments combined with deafness or speech and language problems, and people who are deafblind.

One of the schools within the Kentalis organisation is Rafaël, a school for children with deafblindness, located in Sint-Michielsgestel, the Netherlands. At the moment, the school has 42 students ranging in age from 3 to 20 years. The majority of children (38) have congenital deafblindness.

Rafaël School's mission is: "For every student we want as optimal development as possible to increase their feeling of competence and independence in order to provide them access to a social life. In this way we want to provide the best possible quality of life for every student. We do this by giving the student optimal access to information, communication and mobility. We offer a safe predictable environment, providing competent communication partners that use a tactile oriented approach.

Dialogicality

A Master of Science Program in the Special Education Section of Communication and Congenital Deafblindness started at the University of Groningen in the Netherlands in 2005.

The course provides teachers with tools that help them understand the communication abilities of people with deafblindness so as to help them and their communication partners understand each other, based on a dialogical approach of communication development.

For the authors, three teachers from the Kentalis Rafaël School and alumnus of the Masters program, we agree that this program gave us a lot of extra tools to improve our communicational insights into the daily work with children with deafblindness. Consequently, this concept of dialogicality played a prominent role in each of the three theses described



Left: Eline van Rooij-Cooymans;
Centre:
Ineke Heynen
Right: Odette Haubrich



below. These theses, that build on each other as they were carried out over three consecutive years, were based on clinical research done at the Rafaël school.

1. DIALOGICAL PRACTICE, PAST AND PRESENT:

Quality of dialogicality at a school for children with deafblindness. Eline van Rooij- Cooymans, July 2009

Since the start of deafblind education at Kentalis Rafael in 1962, there have been many influences on the way we developed our ideas about education. Influences of the society we live in, but also people, knowledge, theories and practical approaches have influenced the contact between the teachers and the children with deafblindness.

Important professionals who have had a major influence in the history of Kentalis Rafaël were Prof. Dr. J. van Dijk, Dr. A van Uden and members of the Dbl Communication Network Group. Their educational philosophies and theories still influence today's practice. Going through the historical timeline, it is obvious that some of these approaches are still very useful, some led to new approaches and others have changed completely.

During the last few years professionals in the field of Congenital Deafblindness (CDB) have become more and more inspired by the dialogical approach, mainly based on the theories of Per Linell (1998) and Ivana Markova (2006). According to Markova (2006), the concept of dialogicality is a stronger alternative to more traditional, 'monological' (a

concept used in literature to describe the opposite of 'dialogical') approaches of studying dialogue. In a dialogical model, communication is not just a matter of having a conversation; it considers the characteristics of the human mind, of the multifaceted nature of thoughts and communication.

This research focused on what the paradigm of dialogicality is about and how this was expressed and influenced by the theoretical, practical and cultural context during the history of deafblind education at Kentalis Rafaël.

The research has shown that teachers at Kentalis Rafaël created quality of dialogicality with the students with CDB, in the past and in the present. This was true even if they were following the voice (all those things that

had an influence) of the time, which sometimes gave the idea of a more behaviouristic or monological approach.

2. SCAFFOLDING HEROES:

A dialogical perspective on the developmental potential of three students of the Rafaël School for deafblind children and young adults. Odette Haubrich, June 2010.

The main goal of this research was to determine what we can do as teachers educating deafblind children that may contribute towards establishing their feeling of competence. In other words, how can we help our deafblind students feel like strong and confident people, like heroes even?

In the research I explained why this is important. Although developmental processes are universal, the conditions under which deafblind children grow and

develop are very different. The barriers set by a dual sensory impairment that are in the way of developing a strong, positive and resilient "sense of self" can be extremely high. This study investigated how teachers can deal with these complications during the educational process with these children.

This research was set up based on the dialogical theory, which suggests that every human being has the innate capacity to grow and develop through relationships with others. This is in line with the 'Zone of proximal development' theory of developmental psychologist Lev Vygotsky (1986), which explains how a child can grow when stimulated and helped by the people around them. The term 'scaffolding' is used in Vygotsky's theory to describe this process. His developmental and

dialogical theory formed the base for this study named "Scaffolding Heroes".

The research has shown that a strong stable relationship based on mutual trust established between student and teacher is the most important prerequisite for a the student developing a positive self image; empowering them to feel like heroes. This qualitative research attempted to connect the psychological aspects of learning to the cognitive aspects of learning, an association too often forgotten in education.

3. THIRD VOICES:

Positions and perspectives of professional partners in contact with persons with congenital deafblindness. Ineke Heijnen, July 2011

In recent years, teachers at Kentalis Rafaël were expected to practice the general dialogical approach



as well as the Developmental Follow Up Model, a teaching measurement tool. The purpose of my research was to find out if the way we are influenced by the use of the dialogical approach, was in any way in conflict with the Developmental Follow Up model that was introduced in our school to measure our students' development in an objective way. In my research I used the concept 'Third voices', which is a concept that explains how a person in an interaction takes different roles or positions.

The research made clear that the influence or 'Third Voice' of the dialogical approach compared to the influence or 'Voice' of the Developmental Follow Up model can lead to contradictions. This can happen because the goal-directed third voice of the Developmental Follow Up model does not comply with the more child-directed third voice of the dialogical approach. If the teacher discovers inner contradictions between these so called "Third Voices" and feels tension because of that, he or she should try to find the solution to reduce this tension. But the analysis of the teacher's

reflected utterances of their interactions showed no or little awareness of opposite directedness of third voices. Mostly the teachers were able to stay in the child-directed perspective and were still focussed on the relationship with their student.

Awareness of these so called "Voices" and being able to work out the caused tensions and dilemmas coming from these contradicting "Voices" must be considered as an important skill for the partners of persons with deafblindness.

Conclusion

We three teachers believe strongly that specialized knowledge we have learned about the dialogical approach should become indispensable in the work with students with deafblindness.

As senior teachers we also try to put our knowledge into our daily teaching practice. We have also attempted to transfer this knowledge to our colleagues within Rafaël and to other Kentalis colleagues working with children with deafblindness. Many were involved in the research and

have heard the results of all our work.

We are pleased that this theoretical knowledge on dialogicality has become an integral part of the staff development programs for children with deafblindness within Kentalis.

If you are interested, or want to learn more about the researches we did, please contact us at:

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References

- Linell, P. (1998). Approaching dialogue. Talk, interaction and contexts in dialogical perspectives. Amsterdam: John Benjamin Publishing Company.
Marková, I. (2006). On "The Inner Alter" in Dialogue. *International Journal of Dialogical Science*, 1, (1), 125–147.
Vygotsky, L. S. (1986). *Thought and Language*. Cambridge: MA: MIT Press.

The Nalaga'at Center in Jaffa Tel Aviv

An incredible story

The beginning of Nalaga'at...

As most good stories, Nalaga'at's story began coincidentally. Adina Tal, a director and actress, was asked to teach drama lessons to a group of deafblind individuals, the majority of whom had Usher Syndrome, a disorder characterized by deafness and a gradual vision loss. Adina, who never met deaf, blind – and certainly not deaf AND blind individuals - hesitated. Although she was told her guidance will only be needed for a few months, she tried to delay it. "I will be available only after the Jewish holidays" she answered – the polite Israeli way for saying: "I am not sure about it". Nonetheless, the holidays came and went and Adina started working with the group.

For Adina, these meetings opened a door to a whole new – and fascinating – world. Working with deafblind individuals forced her to break through their



boundaries of darkness and silence - a challenge both for Adina, the group and the touch-sign interpreters. Theater is the art of communication between the actors and the audience!

Together, they started the journey to the unknown, using different theatrical tools and developing a new theatrical language. Adina decided to focus on their everyday lives and on their dreams. One had a dream to be rich; one wanted to be a famous singer, while another just wanted to get up in

the morning and see again. Gadi did not understand her question: "what is your dream?" A few months went by until he finally answered: "I would love to drive a car. "Why a car?" Adina replied, "You should drive a bus!".

Gadi began acting as the group's bus driver. Each student went on the bus as a different character - a mother with her child, a teenager with a walkman, an old man. One student in particular drew Adina's attention. It was Yuri, who went on the bus limping. "Why are you limping?" Adina asked. He answered: "this way I can get a disabled discount"... as if being deafblind was not enough! Adina felt that something very special happened to the group since she began to work with them.

The Bus scene became the closing scene of their first



Nalagaat Centre before renovations



Kapish Cafe



**Nalagaat Centre
after renovations**

show 'Light is heard in Zig-Zag' The show was received with great enthusiasm by the audience and by the critics in Israel and abroad, described as "the most surprising hit of Israeli theater".

Their success led to the creation of the Nalaga'at ('Do Touch' in Hebrew) Non-Profit Organization and, in 2007, the founding of the Nalaga'at Center in the Jaffa port in Jaffa.

Main milestones

In December 2004, The Nalaga'at non-profit organization raised the curtain on the world's first and only theater ensemble whose actors are all deafblind, with its performance 'Light is Heard in Zig-Zag'. The show was invited to perform in Canada, U.S. and Switzerland.

In 2005, Following the show's success and in order to widen the organization's activities, it was decided to establish a home for the group - the Nalaga'at Theater. A deserted

warehouse in Jaffa, property of the Armenian Church, was rented and fully renovated. In parallel, the group started rehearsing for a new production named "Not by Bread Alone". In addition, it was decided that the new cultural center will include a café, which will employ only deaf waiters, and a dark restaurant, where the guests will dine in total darkness and employ only blind waiters.

In December 2007 the Nalaga'at Center, home to the Nalaga'at Theater, opened to the public with its new show 'Not by Bread Alone'. Kapish café and the BlackOut dark restaurant opened to the public alongside the Theater.

In 2009, shortly after opening the center, a new training program started, designed to train deaf waiters from Kapish café and blind waiters from the BlackOut restaurant in theater arts. With their participation, a children's theatrical sign-language

workshop, 'Give a Sign', was launched that year.

In October 2010 the theater introduced the children's performance 'Prince-Rooster', also starring deaf and blind waiters-turned-actors.

In March 2011 the theater celebrated its 500th performance of 'Not by Bread Alone'. This number includes weekly performances at the Nalaga'a Theater, as well as performances at the LIFT Festival in London and the Festival of Music and Theatre in Uijeongbu, South Korea.

What does the future hold for Nalaga'at?

On the 24th of November 2011, a gala night was held at the Center, in which a new ensemble of deafblind individuals composed of Jews, Muslims and Samaritans will perform scenes from a new show named 'Luna Park'. The show is planned to run in parallel to 'Not by Bread Alone' during 2012, extending the Theater's repertoire and enabling more deafblind actors to express themselves creatively on stage, earning their own living, and giving more people the opportunity to learn about their unique worlds.

An additional and unique performance named 'The Banquet' is planned to premiere at the end of 2012. The cast will be composed of deaf waiters and blind waiters, who underwent the Center's special acting training, as well as deafblind actors. 'The Banquet' will present a 'collective Cinderella story' and will be a



celebration of theater, dance and....food!

In order to extend its impact, the Nalaga'at Center is currently in the process of developing new training programs, workshops and courses based on its core values and activities, tailored to different audiences from Israel and abroad. This way, the Center will serve as a national and international model for the inclusion of people with disabilities in society.

Nalaga'at's vision

The Nalaga'at Non-Profit Organization was established based on the belief that all humans were created equal but different and that every person has the right to make his or her contribution to society.

Conclusions

Since its opening in 2004, the Nalaga'at Center serves as a meeting place for deaf, blind, and deafblind individuals and the wide public. They engage in a cultural, artistic and egalitarian dialogue by means of the theatre, café, restaurant and the center's unique workshops and training programs.

The Centre has developed specialized employment frameworks to help deaf, blind, and deafblind people work, develop and earn a living like any other person, achieve self-fulfillment and nurture their unique abilities and talents. It strives for professionalism and excellence in all its endeavors.

It developed values of attentiveness, observation,

and tolerance that lead to personal and social change and acceptance of differences – in others and in ourselves.

Over 70% percent of the Center's budget is generated by self income. As an employer, the Center employs 145 people, of which over 75 are deaf, blind or deafblind. The Center employs people of all races, religions, sex and gender.

Almost a quarter of a million people from Israel and abroad had visited the center and participated in its various activities. Many have declared that their visit had been a significant and transformative experience.

Adina Tal
Director of Nalagaat Stage
for the deafblind
www.nalagaat.org.il

Cast of Prince Rooster

Australia

AUSTRALIAN REPORT



Mike Steer

Australia's National Disability Strategy (2010-2020)

The Strategy which has recently been affirmed by all levels of government sets out a ten year national plan for improving life for Australians with disability, their families and carers. It draws on the results of extensive consultation conducted in 2008-09 by the National People with Disabilities and Carer Council and reported in *Shut Out: The Experience of People with Disabilities and their Families in Australia* (2009). The report is available at

http://www.fahcsia.gov.au/sa/disability/pubs/policy/community_consult/Pages/default.aspx:

The report confirms that people with disabilities in Australia want to bring about a transformation of their lives. They want their human rights recognised and realised. They want the things that everyone else in the community takes for granted. They want somewhere to live, a job, better health care, a good education, a chance to enjoy the company of friends and family, to go to the footy and to go to the movies. They want the chance to participate meaningfully in the life of the community. And they are hopeful. They desire change and they want others in the community to share their vision. They recognise that governments cannot work in isolation and they want others to see the benefits of building more inclusive communities (*Shut Out*, 2009).

The Commonwealth, State and Territory governments have developed this Strategy in partnership under the auspices of the Council of Australian Governments (COAG). The Australian Local Government Association has assisted in the development of the Strategy and there will be a strong role for local governments in its implementation. The shared vision is for an inclusive Australian society that enables people with disability to fulfil their potential as equal citizens.

The purpose of the National Disability Strategy is to:

- establish a high level policy framework to give coherence to, and guide government activity across mainstream and disability-specific areas of public policy
- drive improved performance of mainstream services in delivering outcomes for people with disability
- give visibility to disability issues and ensure they are included in the development and implementation of all public policy that impacts on people with disability
- provide national leadership toward greater inclusion of people with disability.

A summary of the Strategy is available at http://www.fahcsia.gov.au/sa/disability/progserv/govtint/nds_2010_2020/Pages/summary.aspx

Changing the Australian disability rights climate

A transcript of the presentation made at the 2nd Annual National Disability Summit in Melbourne, 15 September 2011 by Graeme Innes AM, Disability Discrimination Commissioner is available at:

http://www.humanrights.gov.au/disability_rights/speeches/2011/summit.html

Individualised Funding for Disability Services

Disability services in Victoria have been undergoing major reform since the early 1990s. A significant reform has been the development of Individual Support Packages (ISPs). People with ISPs can manage the funds themselves and choose the services and providers that best suit them. At least 7800 Victorians have an ISP, accounting for 19% of the Department of Human Services' (DHS) disability funds.

The audit found evidence of good outcomes for recipients and that all stakeholders are enthusiastic about the results of ISPs and their ongoing potential. However, benefits are not consistently delivered. Application processes are

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continued

burdensome, allocation decisions can lack consistency and transparency, and DHS needs greater assurance that funds are spent appropriately. DHS also needs to support and develop the new marketplace in the disability services sector. Current departmental activities and forward planning align with these directions.

More information on the Report is available at:

http://www.audit.vic.gov.au/reports_and_publications/latest_reports/2011-12/20110914_disability_funding.aspx

National Disability Insurance Scheme

In February 2010 the Commonwealth Government commissioned an Inquiry into a long-term care and support scheme for people with disability in Australia. Government's Productivity Commission found that the current disability support arrangements are "inequitable, underfunded, fragmented and inefficient and give people with disability little choice". The report recommends a National Disability Insurance Scheme (NDIS) to provide all Australians with insurance for the costs of support if they or a family member acquire a disability, as well as no fault insurance for anyone who suffers a catastrophic injury.

In its 18 month inquiry into the disability services system, the Commission received over 1,000 submissions. While the Government has yet to endorse its recommendations or commit the additional funding required beyond an allocation of \$10 million to support a newly-established technical advisory group, it is hoped these are the first steps toward an improvement in the provision of support services to Australians with a disability. In the plan set out in the Report the NDIS would be implemented in stages from mid-2014, and not fully implemented until 2018-19.

Payroll tax rebates for businesses who hire employees with a disability

The New South Wales Government has introduced legislation to Parliament that will give businesses a payroll tax rebate for hiring a person with a disability.

NSW Minister for Disability Services, Andrew Constance, said the Payroll Tax Rebate Scheme (Disability Employment) Bill 2011 will provide employers with a payroll tax rebate of up to \$4,000 per employee.

The rebate will apply to businesses who hire a new employee out of the Transition to Work program and will be paid in two equal parts, after three months and after six months from the hiring of a new employee.

To qualify for the rebate, the employee must have commenced employment on or after 1 January 2012 and before 1 July 2016 and the employee should work an average of at least 12 hours a week. The employer must be liable for payroll tax, either during the period of employment or in a financial year during which an eligible employee is employed. The NSW Government has committed \$2 million per annum over the next five years for the scheme to apply from 1 January 2012.

More information at:

<http://www.parliament.nsw.gov.au/prod/parlament/nswbills.nsf/0/BF45C8A3116A435CCA2578A3001CAF06>

A Better Start for Children with Disability

Under the Australian Government's new Better Start for Children with Disability (Better Start) initiative, children aged under six years who have been diagnosed with moderate or greater sight or hearing impairments including deafblindness, Down syndrome, cerebral palsy or Fragile X syndrome will be able to register to access early intervention funding of up to \$12,000 (to a maximum of \$6,000 per financial year).

From 1 July 2011, funding has been available for services such as speech pathology, audiology, occupational therapy, physiotherapy, psychology and orthoptics. Families will have until their child turns seven to use the early intervention funding.

The Better Start initiative also includes a one-off payment of \$2,000 for eligible families living in outer regional and remote areas. As access to services is limited for these families, this payment will assist with travel, home visits and similar expenses.

Eligible children can register for the Better Start early intervention funding by contacting

Australia continued

the Registration and Information Service, managed by Carers Australia, from 1 July.

A number of new Medicare items are also being introduced as part of the Better Start initiative. The new items will be available for children up to the age of 15 provided their treatment and management plan is in place before the age of 13. Families will be able to access the new Medicare items from 1 July 2011.

The Medicare component of the Better Start initiative is being implemented by the Department of Health and Ageing and further information will be available at www.mbsonline.gov.au and www.health.gov.au

For further information about the Better Start initiative, please visit www.fahcsia.gov.au/betterstart

Hearing Services Program

The Commonwealth Government is providing an additional \$47.7million over 4 years to improve access to services in the national Hearing Services Program. This additional funding will help cover increased take up of such implantable technology as cochlear devices; and the age level has been expanded to include adults between 21 and 25 years inclusive to ensure those that are studying, training or establishing their careers are assisted.

For more information go to <http://www.budget.gov.au/>

National Broadband Network and Household Assistance Scheme – Digital Switchover

The National Broadband Network (NBN) is public infrastructure that will provide high-speed access to services such as the internet, electronic home and business applications, e-health records, and research, games, media and other services, to all premises in Australia.

The NBN is being built by NBN Co Limited – a wholly Government-owned company, and most premises will be connected via fibre-optic cable (93%) and the remaining in rural and remote areas will get fixed wireless or satellite connections. The infrastructure is due to be completely rolled out around Australia

by 2020. Customers will still use telco companies such as Telstra, Optus, iiNet and Primus and they will connect users to the new equipment. Consumers will get a Network Termination Device or “NBN box” inside their premises or in a few cases on the outside wall. ACCAN (Australian Communications Consumer Action Network) is a group that is strongly lobbying to ensure that issues for people with a disability are included in the NBN.

ACCAN’s recommendation is that this is an important issue and that deafblind customers think about their use of broadband services now and in the future. In the initial roll-out, implementation of equipment is free to all premises. Any specific equipment currently used, for example, a Vocal Phone Dialer or telephone, will be connected in the same way.

For more information visit www.accan.org.au

Household Assistance Scheme

Government’s Household Assistance Scheme (HAS) provides set top boxes to people on lower incomes or on the Age Pension, the Disability Support Pension or receiving a Carer Payment, who have a disability, seniors and those living in remote areas to ensure they will have uninterrupted access to television as the switchover from analog to digital television progresses around Australia (this is happening currently). The Government will provide recently developed set-top boxes that can be used by blind and vision-impaired citizens to those who need them. The Government will provide installation, in-home demonstrations and access to a free hotline for 12 months after installation of the set-top box.

For more information go to http://www.centrelink.gov.au/internet/internet.nsf/individuals/digital_tv_switchover.htm

Australian Films to be captioned and audio described.

Screen Australia has announced that as a condition of funding from 1 July 2011 it would require films to be delivered both captioned and audio described. It is already an existing requirement for films to be captioned.

Australia continued

This initiative follows recommendations from the Federal Government's Media Access Review final report and provides some 600,000 blind or vision impaired Australians access to an audio described feature film experience in an effort to improve accessibility of Australian feature films. Screen Australia CEO Ruth Harley said, "Better and more equitable audience access to Australian films at a reasonable cost is a benefit for the industry and community as a whole."

The government is funding a national upgrade of cinemas to be caption and audio description compliant by 2013. The new requirement for Screen Australia-funded feature films to be both captioned and audio described will mean that films are available in time for the completion of this upgrade.

Deafblind Student Graduates

Blues enthusiast, Michelle Stevens, has been playing the piano since before she was five. It aided the stress that accompanied studying a Bachelor of Arts at La Trobe University in Melbourne, which could only be undertaken part-time by the deafblind student. The following interview with Michelle and university support staff has been extracted from the university's website:

<http://www.latrobe.edu.au/news/videos/deafblind-student-graduates>

Michelle Stevens:

Quite often people ask me what sort of enjoyment do I get out of the piano? I suppose it is a great release from studying. Studying is not only mentally exhausting at times, but studying also can provide interesting challenges, and playing the piano is actually a great release for some of the tensions that you sometimes feel during study.

Narrator:

Before taking on tertiary education, Michelle had to complete VCE English and a Diploma of Deaf Studies in order to work with tactile Auslan interpreters to access her lectures and tutorials.

Michelle Stevens:

Because primarily my communication is through tactile sign language, I needed to have a very deep understanding of what it was like and to see accurate signs during lectures and tutorials.

Narrator:

Throughout her university career, Michelle became increasingly interested in History and finally chose it as her major.

Jennifer Ridden:

Well, Michelle was really keen to learn and so she was interested in finding out about new things and thinking about things in a new way, and that meant she was prepared to read or use her electronic equipment to read through Braille with the help of the Equality and Diversity unit and through the help of the interpreters and really explore the ideas that were being discussed in the subject. She got more and more excited as the material in the course on riots and rebellions in the British Isles developed and as that material opened up to her, and the excitement was infectious. So we all enjoyed working with her because the more excited she got, of course the more excited we got and that makes it a terrific experience for everyone.

Narrator:

After six years of studying Michelle graduated on the Friday the 25th March 2011. The emotional day was shared by friends family and staff from La Trobe that all played a big roll in supporting her dream.

Jennifer Ridden:

She's put so much work into this degree and she's had so much determination and energy to come to the completion of her degree and I was so proud when she invited me to take part in it and to go onto the stage in my gown to be part of her ceremony.

Sally Freeman:

The Equality and Diversity Centre are so proud of Michelle's graduation. We've been working and supporting her over the last

Australia continued

six years, and for a student who's Deafblind undertaking studies at La Trobe, at University, at any University involves a lot of resources, a lot of staff and it's been a collective effort for her to progress academically so successfully.

Michelle Stevens:

It's really important that people with disabilities must become empowered to make sure that they get the absolute most out of life as one could possibly get, but I quite often think of this that my teacher said to me, "I wouldn't amount to anything, I will always be stupid," and I remember at Glenn College last year at my valedictory dinner, I remember giving a talk to the other students, and I actually said, "I wish I could speak to that same teacher now and show them how stupid I am now".

What ever you do, do not believe people who say you can't do it, you can succeed, as I said quite a few times before, you can succeed and if you put the work in La Trobe will stop at nothing to get the work out of you and to make you succeed.

Senses Foundation – Western Australia

Western Australia's Senses Foundation celebrated this year's International Deafblind Awareness Week by having their State Minister for Disability Services, Hon Helen Morton open a new 'sensory garden' at one of their community houses in the southern suburb of Success. The new facility is an outdoor area incorporating a sensory garden that is tactile and functional, together with an appropriate recreational area that meets resident needs. The garden was developed with generous assistance from local Rotary Clubs, as well as the Gosnells Branch of Rotaract, who were presented with a Certificate of Appreciation at the opening ceremony. The project took volunteers over a month to complete, but transformed the outdoor area into a stimulating and relaxing environment for the three young men in their 20s who are permanent residents. It incorporates such hardscape elements as paving, timber decking, mulch, gravel and

ornamental stones, with a trampoline to provide exercise and stimulation as well as a covered area offering shade and temperature contrast. Plants were deliberately selected with a variety of foliage, form, texture, scent and colour and a water feature and wind chimes were included for additional sensory input. Edible fruits, vegetables, herbs, and spices were also planted to provide sensory and teaching opportunities about plants, cooking and nutrition.

Able Australia – Victoria

Ablephoto is a photographic competition for people with deafblindness and the theme for this year's competition was 'Australia & Me'. An exhibition of pictures was held from Friday 24 June to Sunday 26 June at the BMW Edge Foyer, Federation Square, Melbourne to coincide with the start of Deafblind Awareness Week.

Deafblind Awareness Family/Footy Open Day was held at Able Australia in Camberwell, a suburb of Melbourne in July. The event had a 'Footy' (Australian Rules Football) theme so that everyone dressed in their favourite footy team colours and prizes were awarded. There was also a Mini Expo of the latest technology for people with deafblindness to experience, as well as massage, painting, motorcycles, a handball target, jumping castles, games and food tasting.

Forsight Foundation – NSW

Forsight Foundation Coordinates seven community group homes scattered throughout Sydney from its Group Home Support Centre in North Rocks. It has a new website that can be accessed at: <http://www.forsightfoundation.com.au/index.html>

Trish Wetton, CEO, and Forsight administration staff are currently organising the planning committee for Australia's 2013 National Deafblindness Conference to be held in Sydney.

Senses Foundation recognised at the Commonwealth Heads of Government Visit and the Royal Visit to Perth Western Australia

Australia
continued

The 2011 Commonwealth Heads of Government Meeting (CHOGM) was held in Perth, Western Australia, in October 2011 and Senses Foundation played a role. CHOGM, is a biennial summit meeting of the heads of government from all Commonwealth nations.

CHOGM was the most significant event to be held in Perth since the 1962 Commonwealth Games and the largest gathering of international leaders ever held in Australia. CHOGM 2011 brought together more than 50 world leaders representing approximately one-quarter of the world's countries and one-third of the world's population.

Queen Elizabeth II, who is the Head of the Commonwealth, opened CHOGM as part of a royal visit to Perth with His Royal Highness, the Duke of Edinburgh.

Senses Foundation on display for CHOGM delegates

Approximately 3,000 delegates attended CHOGM 2011 including leaders, foreign ministers, senior officials and support staff.

Immediately prior to the CHOGM meeting, delegates were offered a range of health, sporting, cultural and disability facilities and services to visit. Senses Foundation was proud to be one of three disability services organisations offered for display.

Senses Foundation CEO Presented to the Queen

Senses Foundation Chief Executive Officer Debbie Karasinski was one of five charity leaders presented to Her Majesty Queen Elizabeth II and His Royal Highness the Duke of Edinburgh at a State Reception hosted for the royal couple by Western Australia's Premier Colin Barnett.

Approximately 1,800 of Western Australia's leaders of business, politics, public service,

sport and the arts attended the reception at Government House.

Guests dined on produce from around Western Australian including North West rock lobster, Shark Bay scallops, Brunswick Junction veal fillet, Narrogin Dorper Lamb, and goat's cheese and blueberries from Albany. West Australian actor and singer Lucy Durack, star of the hit musical *Wicked*, sang *God Save The Queen*.

The Premier presented the royal couple with a gift - a book of Eastern Goldfields wildflowers, illustrated by Phillipa Nikulinsky.

Following her presentation to the Royal couple, Debbie Karasinski said that the Queen asked her about the work of Senses Foundation and was very interested in her response.

"I feel incredibly honoured to have been presented to her Majesty and His Royal Highness", Debbie Karasinski said. "It certainly was a once in a lifetime occasion."



“Successful” Sensory Garden transforms a house into a home in Western Australia



The “Success” house – after the creation of the Sensory Garden

In May 2010 Senses Foundation opened its first accommodation facility for deafblind people in the Perth southern suburb of “Success”. The house was specifically designed to accommodate three young men addressing their unique environmental, visual, cognitive and mobility needs.

Originally the outdoor area was undeveloped. Based on our research to ascertain the most stimulating environment for the residents we decided to source funding and assistance to build a sensory garden. Through careful and imaginative design it is possible to create landscapes that

offer a wide range of sensory experiences to people who are deafblind. In sensory gardens, plants and other design elements are selected with the intention to provide experiences for seeing, smelling, hearing, touching, movement and tasting. A great deal of thought was put into identifying the functioning senses of the three clients in the home and how we could best utilise and enhance those experiences for them.

Our vision was for an outdoor area that incorporated a sensory garden, which would be tactile and functional, along with an appropriate recreational area that would

The various components of the Sensory Garden



accommodate our clients' capabilities. We looked at similar projects internationally to gather information on how to create the best experiences for people who are deafblind.

We approached a local service club and they in turn recruited a number of service groups in the area, who all contributed to making our dream a reality.

We incorporated hardscape elements (paving, timber decking, mulch, gravel and stones), a trampoline to provide exercise and stimulation and a shaded area offering shade and temperature contrast. Plant selection was based on a garden design encouraging residents to interact with the plants. We used interesting foliage, shape and form, texture, tastes, aromatic plants, herbs, perennials, climbers and fauna attracting plants. Various colors provided a visual stimulus while adding order and balance, unity, rhythm, focal points, accents, and definition to the garden.

A water feature was added bringing both sight and sound into play along with wind chimes to produce a similar effect. We included edible fruits, vegetables, herbs, and spices that can be tasted, providing both sensory and teaching opportunities.

In reality the world is a sensory garden. Our senses allow us to perceive and experience the world. There are five traditional sensory modes; sight, smell, touch, taste and sound. But there are also other senses, less commonly talked about, just as powerful, if more subtle; the haptic senses (awareness of our body), gravity, temperature, space and enclosure. Our clients have dual sensory loss so the goal was to maximize the sensory experiences in which they can engage and benefit from an environment full of sensory pleasures and curiosities. Our sensory garden is a place where the whole ethos is to encourage the residents to explore, play, touch, pick, crush, smell, taste, and utilize what vision and hearing they have.

Historically many sensory gardens were focused on visual impairments and many designs made the mistake of assuming that because a person has a reduced sensory range they need to over emphasize the remaining



senses. Thus many early sensory gardens focused on too few sensory experiences – failing to appreciate that people with visual and hearing impairments often have some residual vision and hearing that they can effectively utilize. Successful design is largely based on imaginative approaches and finding ways to provide a stimulating setting for all season sensory experiences.

The sensory garden at Success has completely transformed the outdoor area into a stimulating and relaxing environment for the three young men. They particularly enjoy having fun on the trampoline and listening to the water feature for relaxation. Being in the Sensory Garden has presented new opportunities to communicate which in turn helps to alleviate frustration for these clients and reduce some of their challenging behaviours.

One of the young men enjoys the Sensory Garden with a Senses Foundation support worker

Australia
continued

Travelling Ted goes to Brazil

Travelling Ted, Kelly Gurr and Angela Wills visit
Elvira Edwards at the DBI stand at the XV conference



Travelling Ted at the conference

Attending the XVth Deafblind International Conference in Sao Paulo, Brazil at the end of September was an incredible experience. Being relatively new to Senses Foundation and many of the conditions which result in people being deafblind, I found myself soaking up everything that I could see and hear. It was wonderful to meet so many people who are committed to research and sharing their knowledge and experience

with others. I was able to appreciate how an organisation like as Senses Foundation has such passion and drive for enhancing the lives of people who are deafblind. I observed how

the links that are formed and nurtured with other people and organisations as a result of attending a conference such as this enables us to be part of world-wide conversations on deafblindness, supporting research, sharing technology and our experiences from down under.

Whilst attending many workshops on a wide range of topics I found that a workshop which talked about the role of "Interveners" in the state of Utah, USA was intriguing. Senses Foundation is currently working through a "Communications Guides" project and I was able to draw some parallels with the intervener model. It reaffirmed to me the need for research and the value of an evidence base from which to model service delivery.

Kelly Gurr
Manager, Life Skills and Family Service
Senses Foundation (Inc)

Canada

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

As a result of differences in philosophies between the Manitoba Deaf-Blind Association (MDBA) the consumer/advocacy group and Canadian National Institute for the Blind (CNIB) Manitoba Division, the Manitoba Provincial Government offered to work with MDBA to find a new agency to provide services to the acquired Deaf-Blind population.

E-Quality Communication Centre of Excellence (ECCOE) submitted a proposal that the Deaf-Blind program in Manitoba be managed under an interpreter agency. Many of the philosophies of ECCOE were exactly what the Deaf-Blind community was searching for. Under the leadership of Bonnie Heath, the RCMDB was created and Jane Sayer was hired as the Coordinator of Services. This unique program in Canada is now celebrating its 15th Anniversary.

Intervenor Services are provided to adults

who are Deaf-Blind resulting from genetic conditions, accidents, trauma, or other issues. Since the Intervenor Services are overseen by ECCOE, this means the organization has the services of excellent highly skilled Intervenor in all forms of communication, since they have graduated from accredited interpreting programs. One such program is the American Sign Language Interpreter Training Program (AEIP) at Red River College, Winnipeg Manitoba. Staff from RCMDB and deaf-blind consumers present workshops at this Interpreter college to give students first-hand experience to become proper Intervenor. It is understood that not all Interpreters wish to become Intervenor for deaf-blind people upon graduation from this course.

RCMDB came to realize that this high level of training was not always needed for assignments for individuals in the deaf-blind community. Based on the concept

Canada continued



Jane
communicating
with Intervenor

of the Licensed Practical Nurse (LPN), a Service Support Providers (SSP) program was established in 2007. The purpose of this program was to employ trained people, including volunteers, to assist deaf-blind people with such quality of life issues as shopping, bill paying bills, recreation and exercise, doing handicrafts, or even just going out for coffee to get out of their homes and participate more actively in their community. A graduate from Medicine Hat College Intervenor Program, Curtis Hainsworth, was hired to head up this program.

Under the leadership of ECCOE, Executive Director Bonnie Heath, the organization is now pursuing their dream of a service model that will also include Deaf-Blind housing. While this is a dream for the future, the consumer organization knows that today's dreams can become tomorrow's reality!

Jane's Story

As indicated above, I became Coordinator of Services at the RCMDDB fourteen years ago. When the position became open for the second time, I was encouraged to apply, never thinking that I would be hired. I am deaf-blind due to Usher's Syndrome.

The senior staff at my previous employment did not know that I was a Deaf-Blind person. It was a reality of the times that I would have likely been released from my job, despite being a department supervisor in a fairly large company. I was unsure how much longer I could hide this progressing condition. I quit my previous job one month short of being there

25 years to become the RCMDDB Coordinator.

Once I started working as RCMDDB Coordinator I could now be open about my dual disability. It also became an extremely busy time in my life. I enrolled in the University of Manitoba Continuing Education Case Management Program, taking courses at night and weekends, while working all day. I received my Certificate in 2005. I was also on the Canadian National Society of the Deaf-Blind (CNSDB) Board of Directors, 2000-2010, and served as President, 2002-2006.

On June 15th, 2010 in Toronto Ontario I was the very first recipient of the JT Award at the annual JuneFest. This is a Canadian National award named after Joyce Thompson. Joyce was a champion of the disability of deaf-blindness and for consumers for over 30 years.

In my life and in my job, computers, cell phones for text messages and many other technology advancements have enabled me tremendously. I also use Intervenor to help me do my job. I was able to obtain personal funding from the Manitoba Department of Family Services to hire these Intervenor.

I have always believed that persons who are Deaf-Blind need to speak up, advocate and work towards whatever their dreams or goals may be.

Jane Sayer

Note: consumer organizations in Canada use the hyphenated spelling rather than the one word spelling for deafblind/deafblindness

Guatemala **Alex, Ambassador of Deafblindness in Guatemala**

Helen de Bonilla agreed to act as one of the godmothers of a group of Guatemalan orphans. On the day of the baptism she arrived at the orphanage and came upon a small boy that wasn't scheduled to participate in the religious service. "Alex won't know what's going on", explained the attendant. That small boy of four years of age was deafblind.

Helen insisted on holding the frail child during the ceremony, with which the reluctant attendant finally agreed. While they dressed him for the service she waited nervously at the foot of the stairs. How would this little boy react to her? Would he be frightened? What would she do if he started thrashing and crying in her arms? And, would she be repulsed by him when they actually made physical contact?

She looked up as the caretaker brought the thin little boy to the landing. Alex stood alone and a smile, that Helen says she will never forget, lit up his face. In that moment she understood that the essence of joy was not dependent upon physical circumstances. She thought, "If this little child, locked

in darkness and silence, suffering pain, loneliness and fear can experience happiness, then anyone can".

As Alex slept peacefully in her arms during the ceremony, Helen realized how much this little child has already contributed to her life. Something very powerful stirred in her heart. As time went by Helen would make repeated visits to the orphanage; first to bring medicine, later to take the children to appointments for medical exams; but always her primary concern was for Alex. She hoped that the doctors could repair his eyesight and restore his hearing. After several operations Helen had to accept the fact that Alex's condition would never improve.

When he was scheduled for his first eye surgery she couldn't bear to think of him alone, frightened and tied to his crib during his recovery. She obtained permission to take him to her home for temporary care. Alex never went back to the orphanage. In a unanimous decision the entire Bonilla family, Helen, her husband and their five children, decided to adopt Alex.

The enormity of this decision soon

Alex and his loving adoptive sister Diana



Guatemala continued



Alex and his
newly adoptive
parents

overwhelmed Helen. How could she teach him even the most basics tasks? No one in Guatemala could offer advice about how to help a child like Alex. Helen's desperate search led her to the Hilton/Perkins Foundation in Massachusetts. That organization referred her to a group of parents in Argentina with similar concerns.

When she and her husband finally met this dynamic group, they felt that they'd found kindred spirits. Still, there were some who could not understand Helen's persistent motivation to help a child that was not hers by birth. She is an adamant advocate of every child's right to realize his or her full potential.

Encouraged by the Argentine parents, Helen and her husband returned to Guatemala with a mission. They began the difficult task of creating a program to help children like Alex who are challenged with multiple disabilities. FUNDAL (Fundación Guatemalteca para Niños con Sordoceguera Alex) with the help of the Hilton/Perkins Foundation, formally opened its doors in 1998 to Alex and two other children. Today FUNDAL boasts a staff of impressively trained and caring professionals who work with 100 students at their educational center Guatemala City and with 80 children living in the outlying areas of Guatemala.

The professionals at FUNDAL work with children and their families from all the

economic levels in Guatemala. The program aims to provide training and experiences to multiply-handicapped children that will help them understand the world around them and to enhance their function within that world. With this in mind, FUNDAL staff members make personal visits to each student's home. They work, not only with the child, but also with the family member who is responsible for the child.

The progress made by most of the children is slow and may be imperceptible to an outsider, but the joy expressed by parents and teachers over each hard-won achievement is clear. One night a month the parents of Fundal students meet to share not only their wounds, but the healing that is taking place in their lives; to share their frustration as well as their triumphs and joy. Their terrible isolation and that of their children has ended, thanks to Helen and her family – and for the love of Alex.

**Diana Bonilla, Fundal
Foundation for Deafblind Children**

Poster Tradoz de Luz



China

Western Australia strengthens link to China for people with disability



Five representatives from WA's disability sector attended the recent Eighth National Games for Persons with a Disability held in China. I was fortunate enough to be one of the representatives and had the most wonderful time learning about China's

culture, history and attending the Games.

The representatives were in Zhejiang province's capital city Hangzhou to strengthen WA's Sister State relationship with that province. The relationship included a four-year memorandum of understanding (MoU) between WA's Disability Services Commission (DSC) and the Zhejiang Provincial Disabled Person's Federation to gain new perspectives on how to best support people with disability.

The MoU and the Sister State relationship provides a wonderful opportunity for considerable information exchange between the two States. These visits could provide opportunities for future trade between the countries in technology and specialised equipment for people with disability.

Jodi Perkin
Manager Community Living Services
Senses Foundation (Inc)

Romania

Bi-annual meeting of specialists working with deafblind and multisensory impaired children in Romania

As it happens every year, October is the month when we meet teachers who have been involved for many years in the education program for deafblind and multisensory impaired children. It is also a chance to meet new teachers who, at the beginning of this school year, started working in deafblind classes.

This activity, organized by Sense International (Romania) twice a year since 2001, represents a discussions platform where teachers receive updated information in the field of educating deafblind children. They also have the opportunity to share ideas and experiences.

The event, 'Curriculum for Deafblind / MSI children – between Theory and Practice', which took place October 28-29 in Bucharest, brought together 52 participants. Besides teachers from all over the country,

the meeting was also attended by special guests, such as Mr. James Thornberry, Director of Sense International UK and Mr. Romeo Adrian Cozma, Inspector for Special Education from Bucharest School Inspectorate. On his first visit in Romania, Mr. James Thornberry had the opportunity to meet specialists, beneficiaries and decision makers involved in the projects implemented by SI(R) in Bucharest and Timisoara.

The case studies and presentations held by national trainers and teachers working with deafblind/MSI children put special emphasis on practical aspects. Some of the topics presented included: sensory stimulation for newborn babies, learning by playing and sensory-cognitive education activities, interdisciplinary work (considered an essential element for applying the curriculum), developing of basic living skills,

Romania continued

developing mobility and orientation skills. As a novelty element, the Wilbarger Protocol was described as an intervention technique for sensory defensive children.

The meeting was interactive, consisting of a workshop session on Vocational aspects for deafblind/MSI young people. Organisers and participants raised the issue of their future possibilities and opportunities for community integration following school graduation. Teachers suggested areas of activity and trades that could be appropriate for deafblind/MSI youth, presenting arguments to support their suggestions.

On October 29, participants visited the Kindergarten for Children with Hearing Impairments in Bucharest, where SI(R) supports the Early Intervention Support Centre and two deafblind/MSI classes. Participants were presented case studies showing the children's progress from the intervention. This is how the event ended to the guests delight. We are looking forward to the next one, in March 2012.

“The event, ‘Curriculum for Deafblind/MSI children – between Theory and Practice’, which took place October 28-29 in Bucharest, brought together 52 participants”

James Thornberry addressing the meeting



Acquired Deafblindness Network

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Siblings Network

Sabine Kersten reports

The XV Dbl World conference in Sao Paulo was a chance for some siblings to meet and to share experiences and information.

During this conference there also was a display of books for sale on deafblindness. Some siblings went to see what has been written on siblings of children with deafblindness. They were surprised to find out there were no books on this subject. There was no information for the brothers and sisters.

Brothers and sisters have a constant need for information. Just like parents and professionals, their need for information changes as they grow up as conditions and situations change over time. A 6-year old sister may have some questions about why her 8-year old brother is not attending the same school. A teenage boy may have some questions or concerns for his little brother or sister who does not have friends like he has.

One of the goals for the Siblings Network is developing information for siblings. For this we do need the support of professionals, organisations, parents and of course siblings themselves.



Are you a sibling and willing to share your experiences? Or do you know a sibling who could benefit from this sharing opportunity? Please do contact us. Your experience will show others that they are not the only ones having questions and concerns, and this sharing will be very helpful for them.

We are looking forward to getting to know you!

Sabine Kersten
siblingsnetwork@gmx.net

“One of the goals for the Siblings Network is developing information for siblings. For this we do need the support of professionals, organisations, parents and of course siblings themselves”

CHARGE Network

Andrea Scheele-Wanka reports

The CHARGE Network held a meeting during the Network period set aside during at the XV Dbl Conference in Sao Paulo Brazil, September 27, 2011

Andrea Scheele welcomed new members to the Network and facilitated the discussion. A sign in sheet was distributed to create a contact list of the individuals and countries represented.

Andrea reported that the website (proposed domain name as: www.dbicharge.org) is under construction, with the cost of development being shared by SENSE UK and Perkins School for the Blind.

The basic format of the website will include: links with parent groups from other countries (UK, USA, Germany etc); topic of the month; review of published articles; updates on ongoing research topics; a forum for discussions, question and answers; news information about upcoming conferences, family weekends, workshops, etc.

Andrea reviewed the topics of interest from the last meeting and a priority list was created as follows:

- Communication/language, choice making
- Diagnosis
- Eating and drinking challenges
- Education, school type, challenges and curriculum
- Relationships between parent and child
- Therapies: OT, PT, and Speech
- Sensory Integration

Andrea reported that the Dbl CHARGE Network has a position on the Dbl Board for the next four years.

Information Sharing:

- The Nordic countries have created a group that gets together to share information. In Norway, the focus is on the medical aspects of CHARGE coming under the National Health Care System. Their goal is to work together to combine both medical and educational issues. A video was shown about young adults with CHARGE, describing their ongoing needs and the types of placements available for these young adults. The Nordic representatives indicated that it is a challenge to sustain a parent group in that region due to their geographic challenges.
- In Germany a Parent support group has been organized. The parents support each other as best they can at workshops and meetings.
- A teacher from Brazil reported working 1:1 with a young boy with CHARGE Syndrome. She shared the challenges she faces as there are so few children with CHARGE in the region where she works. She shared a beautiful photo album of the student she works with. She also indicated that there was a small support group of mothers who have children with CHARGE in her area.
- SENSE UK recently hosted their very successful first National Conference. A number of professionals and approximately 60 families were in attendance. It was reported that the CHARGE family network in the UK is strong. It is supported by SENSE which hosts family networking



days 4 times per year.

Professionals from SENSE also work in hospitals and implement a program called "All about Me", part of the Passport Program.

- The USA has a very active parent run CHARGE Syndrome Foundation. This Foundation hosts a conference every 2 years. Professionals strongly support the efforts of this conference. The conference this past year was the largest one to date, with family participation having dramatically increased.

Andrea closed the meeting by indicating that the common goal of the Dbl CHARGE Network is to establish family networks in all of the member countries; offering family support activities and workshops where required.

The Dbl CHARGE Network Group agreed to these next steps:

- 1) formalize the email list
- 2) complete the website and create the links
- 3) focus on the following topics in the next several months:
 - a. Cochlear Implants
 - b. Identify children with CHARGE Syndrome and help families build local networks
 - c. Discuss issues related to eating and drinking

Contact information:

Andrea-Wanka@dbicharge.org
Martha.Majors@Perkins.org

Communication Network

Ton Visser reports

The members of this Network met each other in October at the University of Groningen, The Netherlands. During the week we were there, five students graduated from the Master in Educational Science – Communication and Congenital Deafblindness. I am happy to tell you that five members of our Network delivered lectures at this University Program.

One of the issues we should like to see occur in the near future is a Post Masters Program for those who completed their Masters on this topic. We hope it will be possible to organize yearly meetings with the Post Masters students where they would discuss theoretical developments in our field as well as practical applications of these developments. It would be preferable if these meetings would occur in association with Dbl Conferences. Post Masters Students who support this idea are invited to contact Marlene Dealman or Anne Nafstad.

In March 2012 we plan to meet again. One important issue on the agenda will be the future of our



Network. Besides myself, Jacques Souriou and Inger Rodbroe are also retired now. This means that we are no longer connected with an organization. What the implications are for our Network we will discuss in March.

Also at this meeting we will discuss the possibility of starting an open access journal. We also understand that over 100 universities are using these open access magazines. It appears that

there is very good software now to undertake such an initiative. The good news is that three staff members from the University of Groningen have offered to help us start such a magazine.

After our meeting in March we will inform you about our future plans.

Ton Visser
asmvisser1948@gmail.com

“We hope it will be possible to organize yearly meetings with the Post Masters students where they would discuss theoretical developments in our field as well as practical applications of these developments”

European Deafblind Network (EDbN)

Lucy Drescher reports

EDbN (the European Deafblind Network) is a network of deafblind people, families and professionals working together to raise the profile of deafblindness as a unique disability in Europe and to ensure the needs of deafblind people are included in all the policy making work of the European Union. Our vision is that deafblind people and the significant people in their lives across Europe should have equal rights and be able to fully participate in society.

EDbN is organised by a Chair and a Steering Group and the membership are all part of an email group. The Chair of EDbN is just in the process of changing at the moment. The Steering Group includes Ricard Lopez, Lucy Drescher, Ursula Heinemann and William Green. We are always looking for new members so do let us know if you would like to get

involved.

EDbN is a member of EDF (the European Disability Forum), which is the umbrella organisation representing disabled people at a European level, and the Chair attends the EDF General Assembly each year. In addition to this, Ricard Lopez is part of the EDF Structural Funds working group and he really needs to hear from anyone who has knowledge in this area. In 2012 the European Commission has stated its intention to put forward an Accessibility Act. We will plan to do lobbying work on this and so will be looking for knowledge of ICT and manufactured goods. EDBU (the European Deafblind Union) are also members of EDF and EDbN is in the process of signing a Memorandum of Understanding with EDBU, to commit us to sharing knowledge and co-operating on relevant issues. EDbN is also part of a group



setting up a European Platform representing Deaf, hard of hearing and deafblind people.

EDbN has also been part of the organisation of the Listen to Me family events that have taken place in Italy, Spain, Scotland and the Czech Republic, to enable the sharing of experiences and good practice.

EDbN produces an e-newsletter entitled 'Deafblind Europe'. To subscribe or contribute articles please contact the editor, **Ricard Lopez at rlopez@sordoceguera.com**

Outdoor Network

Joe Gibson reports

In September 2012 Sense Scotland is planning an outdoor event in the Highlands of Scotland. I am proposing that the Dbl Network collaborate with Sense Scotland to make this more of an international event. This would be the opportunity to meet others who enjoy being outside and to share the experiences of a

range of outdoor activities. To aid with the planning of the event, please contact me to indicate your interest. Check out Sense Scotland website <http://www.sensescotland.org.uk/> for more information.

Dr. Joe Gibson
Dbl Outdoor Network
jgibson@sensescotland.org.uk



Employment Network

Diana Bonilla reports

It is my pleasure to introduce myself as the new contact person for the Employment Network. I want to thank the past network contact, Seija Troyano from Finland, for her trust and guidance.

On behalf of the network I invite participants to send me:

- As many models as possible to show what Deafblind people can do or are now doing as their work.

- Short stories and pictures about Deafblind people working in different countries.
- Listing of products that can be purchased (ie technology, training guides or courses, etc).

I am looking forward to hearing from you and to share good practices all around the world.

Sincerely,

Diana Bonilla, Guatemala
comunicacion@fundal.org.gt



Latin American Network

Sandra Polti reports

The Latin American Network began October 13, 1999. It has some 184 members representing the countries of Perú, Colombia, Brasil, Chile, Argentina, Ecuador, México, Guatemala, Venezuela, Spain, Uruguay, among others.

The principal objective of the network is to foster communication among parents, professionals and other people working with individuals with deafblindness and multiple disabilities. A further objective is to provide information to these members about deafblindness issues.

During the time the network has been active, much has been shared with the membership, including the activities and events

going on in Latin America. Various pieces of information has been shared with the membership about deafblindness, pedagogical programs, various services available, the role of intervenors and guide interpreters, status of congenital rubella syndrome, etc. Members have been advised about the information that has been published about deafblindness in Latin America and elsewhere.

The Network's plans for 2012 include:

- a) Appointing a parent to represent the parent group.
- b) Developing a new definition of deafblindness, recognizing it as a unique disability.
- c) Working towards the establishment of better services, with an improved focus on social

and academic inclusion.

d) Strengthening our team work. This will involve improving the interaction among parents, other family members, professionals, members of the community and persons with deafblindness and multiple disabilities.

e) Promoting the importance of deafblind awareness and advocacy among family members and professionals. Develop deafblindness related guidelines to be included in the curriculum for teacher training studies at college.

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Rubella Network

Nancy O'Donnell presents the following reports

Liliane Grangeot-Keros - France

In France, we still have sporadic cases of rubella infection during pregnancy leading to medical abortion or newborns with CRS. Our last case of rubella infection during pregnancy was laboratory confirmed at the end of October, 2011! Furthermore, in 2011, a large epidemic occurred in Vietnam and in Tunisia. In Vietnam, they don't have a rubella immunization program. In Tunisia, only immunized young women are immunized. Many rubella cases from Tunisia are confirmed in our Paris laboratory. I am sorry to say that rubella is far from eradication, especially in Africa.

Pat Tookey – UK National Congenital Rubella Surveillance Program

Here in the UK we are seeing a continuing gradual improvement in MMR uptake rates. They are now over 90% nationally (though with pockets of much lower uptake) for the 1st dose by 24 months of age, which is the highest we've seen since 1997. In terms of congenital rubella cases, we are still getting one or two reported a year. Most of these are either infants born to women who have been in the UK for a relatively short time, or are infants whose mothers acquired infection abroad in early pregnancy.

Joff McGill – Sense UK

The UK has seen uptake of the MMR vaccination reach 90% for the first time since 1998. This is very welcome news but it does

mean a significant cohort, built up over 13 years remain unvaccinated and potentially at risk. The reality of this is confirmed with ongoing measles cases, linked to outbreaks in Europe, affecting those who have been unimmunised. Sense continues to work with the Department of Health to promote immunisation against rubella and ensure any at risk groups are protected. We have produced a joint leaflet with the NHS targeted at those thinking of getting pregnant, we are concluding a project promoting rubella immunisation to ethnic minority communities and we published an article in a newsletter health professionals reminding them that every time they talk to young people about immunisation is an opportunity to offer protection against rubella.

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_127517

GAVI, the global alliance on vaccines and immunisation, have decided to open a funding window for the rubella vaccine.

Availability of funding for rubella vaccine will prevent the sight and hearing loss, along with other disabilities at birth, that result from rubella infection in early pregnancy. It gives a much-needed boost to countries' efforts to eliminate both measles and rubella.

It means that 57 countries eligible for support can apply for funding to introduce these vaccines into their national immunisation schedules, with support available from the World



Health Organisation.

Congenital Rubella Syndrome remains a major public health problem with an estimated 112 000 cases occurring globally, of which 90 000 are in "GAVI eligible" countries.

While large-scale rubella vaccination during the last decade has enabled the elimination of rubella and CRS in the Western Hemisphere (the Americas) and several European countries, the current burden of CRS in Africa, South-East Asia and the Western Pacific regions is still thought to be high.

<http://www.gavialliance.org/library/news/press-releases/2011/gavi-takes-first-steps-to-introduce-vaccines-against-cervical-cancer-and-rubella/>

WHO News Release: November 17, 2011

WHO supports GAVI Board decision to open a funding window for human papillomavirus and rubella vaccines

17 November 2011

"The decision by the GAVI Board to invite countries to apply for funding for introduction of human papillomavirus and rubella vaccines is great news for developing countries. The protection afforded by the HPV vaccine will save many more women from the pain and suffering caused by cervical cancer. Availability of funding for rubella vaccine will prevent the severe birth defects that result from rubella infection in early pregnancy and give a much-

needed boost to countries' efforts to eliminate both measles and rubella."

Dr Flavia Bustreo, WHO Assistant Director-General, Family, Women's and Children's Health

For more information check out: http://www.who.int/immunization/newsroom/GAVI_hpv_rubella_statement_nov11/en/index.html

Pan American Health Organization Updates – Newsletter, Vol. XXX111 No 4, August 2011

The Region of the America's celebrated the two-year anniversary of the interruption of endemic rubella circulation, with the last confirmed endemic case reported in Argentina in the last week of January, 2009.

For 2009, Canada and the United States reported 4, and 3 import-associated rubella

cases, respectively. In 2010, 15 rubella cases were reported in the Americas (Canada-7, French Guiana-1 and USA-7). In 2011 (up to mid-June), a total of 4 rubella cases were reported, all imported into the United States.

As a result of the previous rubella outbreaks, in 2009 27 CRS cases were reported: 13 in Argentina and 14 in Brazil. No new cases of CRS were reported in 2010

One CRS case was reported in Manitoba, Canada in 2011.

Nancy O'Donnell, Helen Keller National Center - USA

In the U.S., we continue to receive emails from adults who are, for the first time, wondering if their unusual and unexpected health problems are somehow related to their mother's rubella infection during pregnancy. Many of these adults experienced mild hearing and/or vision issues

throughout their lives, but nothing that stopped them from living a "typical" life. Now, in their mid 40s, they are experiencing what they consider "unusual" health problems that were not anticipated in light of family history, lifestyle or age. Our information on late onset health concerns in adults with CRS has been referred to as the "missing piece" in the puzzle. Our listserv for individuals with CRS can be a helpful place to tell their story and to find information and support.

A recent discussion on our professional listserv talked about documenting the causes of death of individuals with CRS. We would be interested to know if any countries or agencies are maintaining this information.

Nancy O'Donnell
Chair, Rubella Network
nancy.odonnell@hknc.org

Compendium on CHARGE Syndrome

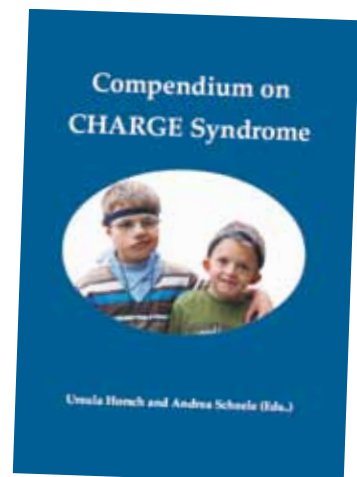
(Multidisciplinary and international perspectives)

Ursula Horsch & Andrea Scheele (Eds.)
1st edition 2011 · 300 pages · paperback
ISBN 978-3-941146-15-0

This compendium covers multidisciplinary and international perspectives on CHARGE Syndrome. It is an English version of the original German language publication. Special sections are presented on genetics, cardiology, urology, visual and hearing-related perception, phoniatrics, cochlear implantation, research on dialogue training in early educational processes, multi sensory impairment and deafblindness. The volume also focuses on cognitive semiotics, challenging behaviour, parental

perspectives, music, emotions and supervision. Articles on endocrine system involvement, balance, physical education and sports complete the editors' selection.

Authors: Prof. Dr. Boulos Asfour, Prof. Dr. Frans van Erckelens, Prof. Dr. Margit Fisch, Dr. Silke Riechardt, Prof. Dr. Jürgen Kohlhasse, Dr. Silke Pauli, Prof. Dr. Barbara Käsmann-Kellner, Prof. Dr. Roland Laszig, Prof. Dr. Rainer Schönweiler, Prof. Dr. Joachim Thüroff, Dr. Christian Thomas, Prof. Dr. Antje Aschendorff, Dr. Susan Arndt, Prof. Dr. Timothy Hartshorne, Prof. Dr. Jeremy Kirk, Dr. David Brown, Prof. Dr. Lauren Lieberman, Prof. Dr. Pamela Haibach, Dr. Anna Wolff, Martha Majors, Adele Farhart, Flemming Ask Larsen, Hanne Pittroff, Hansjörg



Meyer, Prof. Dr. Ursula Horsch and Dr. Andrea Scheele.

The table of contents can be viewed at: www.median-verlag.de. Purchases can be made through email at vertrieb@median-verlag.de or through www.amazon.com. Publication cost 41 Euros + cost of delivery.

Announcement: Formation of New Confederation of Parents



On October 1, 2011, the formation of a new organization representing all parents who defend the rights of their deafblind multi-disabled sons and daughters was announced. Thanking for the presence and support of the Presidents of Deafblind International and World Federation of Deafblind, Ricard López, the representative of the Dbl European Deafblind Network (EDbN) announced the news at the closing ceremony of the XV Deafblind International World Conference in the city of Sao Paulo, Brazil.

This new world organization or confederation consists of the following regional federations: Federación Latino Americana de familiares de personas con Sordoceguera o Discapacidades Múltiples (15 countries comprising the Latin American Federation of families of the Deafblind and the Multi-disabled), 27 countries representing the Dbl European Deafblind Network (EDbN), Canadian Deafblind Association (and its 6 Chapters) and the 3 countries that form the African Federation of Parents of the Deafblind. The purpose of this new organization, whose headquarters has been established in Barcelona, Spain, is to provide a voice for all parents whose sons or daughters have this disability. Through this organizational network, parents will gain assistance from other parents. They will learn best practices towards working with their governments to ensure that their children live independent lives and receive adequate public health, education and financial support.

The **World Confederation of Parents of Deafblind and Multi-Sensory Disabled Persons** (WCPDB) has now taken its first steps (www.wcpdb.org) and invites every organization in this field to join in.

Deafblindness is a condition that combines in varying degrees both hearing and visual impairment. Two sensory impairments multiply and intensify the impact of each other creating a severe disability which is different and unique. Numerous studies indicate that the prevalence of deafblindness is around 40 per 100,000 people.

For more information or to request an interview please send an email to rlopez@sordoceguera.com or call +34 93.331.73.66. Follow us on twitter @WCPDB

A co-ordinated research strategy

to explore aspects of the impact of deafblindness across a range of different groups and ages of people

Some of the delegates of the recent Dbl world conference in Brazil will have met Anna McGee, Sense UK's head of research. Anna has been establishing the Sense research strategy which follows research commissioned by Sense (Robertson & Emerson, 2010). Robertson and Emerson noted that the numbers of deafblind people had been severely under estimated in the UK and so Sense has implemented a research strategy in response.

The strategy aims to build on our experience of a life long partnership between deafblind people, their families and those that support them. Sense has always, and will continue to ensure that we work in partnership with others to build new knowledge, share it, to empower individuals and to create change where change is needed.

There are currently three externally funded projects being conducted by members of the Sense research team:

The Rubella Immunisation Project

This project is developing strategies to inform ethnic minority groups who are particularly vulnerable to rubella infection, to encourage them to take up the MMR immunisation.

The Older Peoples' Project in conjunction with BUPA, has focussed on older people in residential care homes. It adapted a screening tool originally developed by Else Marie Svingen and her colleagues at the Skadelen Resource Centre in Norway, and

has interviewed people who were found to have sight and hearing loss, and their care staff, to identify their needs.

The Congenital Research

Syndrome (CRS) Project is a small project that will build on our current knowledge about CRS to inform doctors about the potential for some particular health difficulties that maybe experienced later in life.

Five new projects, funded by Sense, have been started and we hope the projects can play a part in contributing to the worldwide research community. The projects are intended to support deafblind people themselves, their families and other stakeholders.

The first project is an investigation into the provision of opportunities for parent/infant joint attention in a tactile modality rather than a visual or auditory one and is being undertaken by Glasgow Caledonian University.

The development of a functional assessment approach for deafblind children is the second project in the schedule, and is being carried out internally within Sense, by using external expert analysis of Sense's approach to assessment.

The third project, which is being undertaken by Birmingham University, consists of an investigation of self-identity in people with Usher syndrome and the extent to which a diagnosis of Usher alters a person's perception of self and/or their intended life plans.

The fourth project will evaluate the factors that lead to older people with acquired dual sensory loss remaining in the community rather than entering residential care.

The final project is an investigation of the ways in which the Social Haptic method of communication is used by deafblind people, and Derby University have starting work on this.

A peer reviewed journal on deafblindness

We are also delighted to announce that we are proposing The Journal of Dual Sensory Impairment. We are already in discussion with a publisher and a number of our international colleagues about the journal and we thank you for your encouraging comments. Once the proposal is accepted by the publisher we will establish an editorial board with joint editorship, a truly international flavour, and independence from Sense. We expect to launch the journal towards the end of 2012.

Finally the theme of the recent Deafblind International World Conference was 'Inclusion for a Lifetime of Opportunities'. We hope Sense's research strategy can be viewed as an attempt to establish and undertake robust research activities that will contribute to greater understanding of the lifetime opportunities of deafblind people and how barriers to full inclusion in society can be eradicated. We look forward to working with Dbl and its members on this journey.

Bridging the Knowledge Gap:

The Global Disability Rights Library

How much of your valuable time do you spend thinking about how to find answers to your questions? If you have easy Internet access, you probably just fire up your laptop or grab your smart phone and Google it without a second thought. How often have you been blocked from accessing information that you know could benefit hundreds, or even thousands, of people with disabilities? That's the dilemma confronting disability rights advocates and policy makers in developing countries who don't have Internet access or have access that is too slow, expensive, or unreliable. Deafblind International is doing its part to support an initiative-the Global Disability Rights Library (GDRL) project-that is working to close the knowledge gap.

The GDRL project is a joint initiative of the United States International Council on

Disabilities and the WiderNet Project at the University of Iowa with funding from USAID. The GDRL is part of a massive digital library called an eGranary. The eGranary has an interface that allows users to access websites, documents, videos and more without requiring Internet connectivity. Deafblind International is proud to help the GDRL become a more valuable resource for organizations and policy makers fighting for the human rights of people with disabilities by allowing the use of its website in the off-line digital library.

The on-line version of the GDRL has been available since June and can be viewed at <http://gdrl.org>. The off-line version has been deployed to 10 locations and 50 more sites will be added by early 2012. Both the off-line e-Granary Digital Library and the on-line version of the

library have been designed to be accessible to users with disabilities.

If you would like to learn more about this innovative project that has the potential to change the lives of thousands of people with disabilities in developing countries, please visit <http://www.usicd.org/index.cfm/global-disability-rights-library>

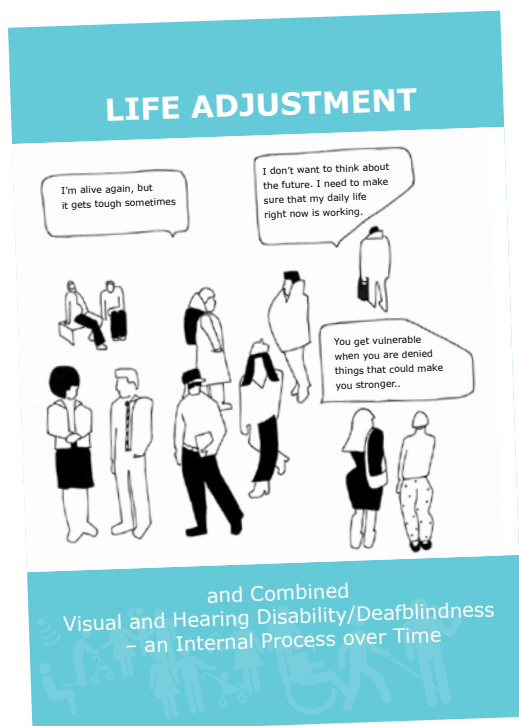
If you would like to be aware of future opportunities to apply for a free, off-line digital copy of the GDRL for organizations in developing countries, then sign up to be notified at <http://www.widernet.org/digitallibrary/GDRLSiteSelection/>.

Please feel free to email us at GDRL@USICD.org with questions and suggestions with information to include in the GDRL, or to learn more about how you can be involved.



Nordic Centre for Welfare announces the publication of a new book

on life adjustment for individuals with acquired deafblindness



On November 9, 2011, the Scandinavian Network on Acquired Deafblindness launched the book *Life Adjustment and Combined Visual and Hearing Disability/Deafblindness – an Internal Process over Time*. The book is the result of a three-year project on life-adjustment processes in connection with acquired deafblindness. It describes the stages a person typically goes through when suffering from a progressive disorder.

In an era where user participation is often the talk of the town, it is nice to see an example of users being actually represented in all

phases of a project. The book is based on interviews with 15 people with deafblindness from across Scandinavia. Furthermore, a reference group of four deafblind women worked closely with the authors, and each of them gave a lecture at the seminar which celebrated the release of the book.

The authors of *Life Adjustment and Combined Visual and Hearing Disability/Deafblindness*

– an Internal Process over Time are: Ann-Christine Gullacksen (Sweden), Lena Göransson (Sweden), Gunilla Henningsen Rönnblom (Norway), Anny Koppen (Norway), and Anette Rud Jørgensen (Denmark). The reference group consisted of Linda Eriksson (Sweden), Nina Skorge (Norway), Monika Steorn (Sweden) and Britta Vestergaard (Denmark).

The book is published by the Nordic Centre for Welfare and is available in English, Danish, Swedish, and Norwegian. The book is free and can be ordered at nvcdk@nordicwelfare.org

Text: Lasse Winther Wehner
Photo: Fredrik Sjögren



SSPs: What Are They and Why Are They Necessary?

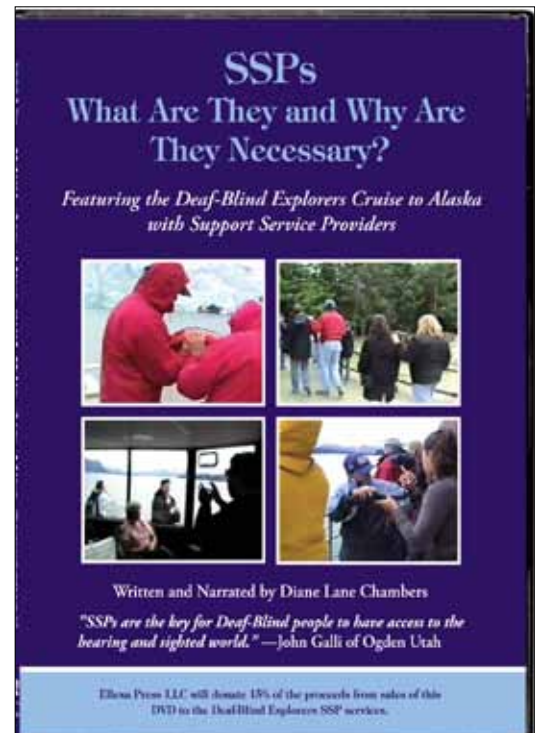
Written and Narrated by Diane Lane Chambers

It's estimated that 1.2 million Americans are both deaf and visually impaired. Dealing with this dual sensory loss can be challenging at the very least and devastating at its worst, causing profound isolation and loneliness. Support Service Providers can make a huge difference in improving the quality of lives for individuals who are Deaf-Blind

This informative and engaging documentary chronicles travels with the Deaf-Blind Explorers vividly portraying how support service providers work with Deaf-Blind individuals, whether they're on a bus, a whale-watching excursion, a tour through a rainforest, or on a thrilling dog-sled ride!

Personal testimonials by Donna Ragland, from Morrison Colorado, and other Deaf-Blind travelers, describe the value of support service providers: how their services enable them to access the world around them, participate in their communities, and maintain and enjoy an active life.

Now available online at www.ellexpress.citymax.com



What is an intervenor?

A new DVD has been produced by the Children's Specialist Services team at Sense in the UK, to explain the very specialist role of an intervenor. The DVD includes examples of intervenors working on a one to one basis with deafblind children and adults and interviews with deafblind people, parents, intervenors and other professionals working in this area.

The DVD includes sections on what an intervenor is; what intervenors do in education and in social activities; what the training to become an intervenor involves in the UK; how intervenors work

with families and includes examples of intervenors working with both children and adults.

This DVD can help you to understand more about the role of an intervenor and it can also enable you to explain the role to others.

If you would like to purchase a copy of this DVD please contact the Sense Information Service by



emailing them at info@sense.org.uk or by telephoning 00 44 845 127 006. Alternatively you could write to them at Sense Information and Advice Service, 101 Pentonville Road, London N1 9LG, UK.

Vice President Bernadette Kappen reports

Growing and thriving are the two words I think of when I reflect on the work of Deafblind International (Dbi). The World Conference in Brazil brought together people from all parts of the world. The sharing and learning was evident in every corner of the hotel. Each presentation offered new information and updated the participants on research in a variety of areas. The Conferences will continue to be an important benefit of being a member of Dbi.

Over the past four years, Dbi has been working on a strategic plan to promote the needs of individuals who are Deafblind around the world. The advocacy initiative is putting the needs of individuals out in front of government officials. Individuals who are Deafblind, their family members and professionals are being seen, they are being heard and they are taking a stand. It is so exciting to see how the services are expanding. There is still a lot of work to be



Vice President Bernadette Kappen

done and with the support of the Board and individual members of Dbi we will continue to be successful.

The organization is thriving because of the dedication and support of so many people in the field. As a group, Dbi works cooperatively and with this approach so much can be done. Communication is essential to our growth and over the next four years, we will work on using the website as a vehicle to share information as well as

fostering local and regional opportunities for people to share information.

Collaborating with the World Federation of the Deafblind and ICEVI will help expand Dbi's reach. Throughout the world organizations are being encouraged to work together and we can say that Dbi has been doing this for the past several years.

I hope you will consider becoming an individual member of Dbi or encouraging your organization to be a corporate member. Dbi is your link to information about programs and services for individuals who are Deafblind. Your support will assist us further growth and increased opportunities. It is an exciting time!

“Throughout the world organizations are being encouraged to work together and we can say that Dbi has been doing this for the past several years”

Vice President Carolyn Monaco reports

When I returned home to Canada from my first Deafblind International (DbI) conference in 1984 in New York City, USA I never imagined that 27 years later I would return from the 15th DbI international conference in Sao Paulo, Brazil as one of two vice presidents of this organization.

I remember the events of 1984 like it was yesterday, the excitement with which my colleagues and I registered for the conference at the urging of our then bosses, John and Jacque McInnes. I remember their words, "you'll never regret it". I never have. In fact, every time I return from a conference

with updated information and materials, renewed enthusiasm and wonderful memories of international locations and friendships I am reminded of how grateful I am for those words of encouragement so many years ago.

I hope that amongst the attendees at the 15th DbI Conference in Brazil that there was a young, enthusiastic individual who was inspired by the experience to continue to pursue a lifelong career in a field filled with exciting challenges, fulfilling rewards and the support of a group of people who are second to none. I'm sure, they'll never regret it!

I am both honoured and humbled to work amongst such an



esteemed group of people whose common goal of improving the quality of life of individuals who are deafblind, no matter where they are in the world, is at the forefront of what they believe in and what they do.

I look forward to working closely with Gill and Bernadette, the members of the Management Committee and the Board during the next four years as vice president. Many thanks for the opportunity.

New and improved DbI website recently launched

After months of work, Deafblind International (DbI) is proud to launch our new website look! There were many changes made that visitors will enjoy including:

- a clean, completely redesigned layout that is easy to read
- a new, simplified main navigation structure that makes finding the information you want quicker
- sample articles from recent editions of our flagship magazine, DbI Review
- a members page established where members could receive



their DbI Review online

- quick access to our social media links (Facebook and Twitter)

We invite you to visit our site (www.deafblindinternational.org) and let us know what you think! We invite suggestions for further



improvement.

Stan Munroe
Information Officer

Prestigious awards presented at the XV Dbl Conference

Sao Paulo Brazil, September 30, 2011

During the Gala Dinner at the XV Deafblind International Conference in Sao Paulo, Brazil, recipients of the Dbl Lifetime Achievement and Distinguished Service Awards were honoured. The Lifetime Achievement Award is presented to an individual who has made a distinguished contribution to services for deafblind people on a national and international level. Previous to 2011, there have only been 4 persons honoured with this award. The Distinguished Service Award is offered to people who have significantly contributed to the deafblind field, or Dbl, internationally.

Lifetime Achievement Award

The Lifetime Achievement Award was presented (in absentia) to Mari Saethre of Norway. Mari devoted her entire career to working with individuals who are deafblind and their families. She is one of the pioneers who built the educational program in Norway. As a young woman she started her career living with the first deafblind children who were identified with Rubella.

Her skills developed at the Home for the Deaf in Andebu contributed towards developing the educational program for deafblind children at Skadalen School

in Oslo, where she worked as a special pedagogue for 13 years.

Following retirement she continued working as a research assistant looking through hours of video tape to gain additional insight into the spontaneous gestures and natural communication expressions of the children.

Mari Saetre is now 80 years old. She has inspired everyone she has worked with and there are few people in the field of deafblindness who can look back on a lifetime career with the same focus – the professional dedication for congenitally deafblind children.

Mari Saetre receives her Dbl Lifetime Achievement Award at a later event in Norway





Lex Grandia receives the Distinguished Service Award

Distinguished Service Award

Distinguished Service Awards were presented to Lex Grandia (Denmark), Shirley Rodrigues Maia (Brazil) and Bernadette Kappen (USA)

Lex Grandia is the first person with deafblindness to receive the Distinguished Service Award. Throughout his career he has enriched the lives of so many individuals who are deafblind as well as the professionals who work in the field.

After receiving a Ph.D. in Theology in the Netherlands, Lex worked as a counselor and part-time minister. He started his work with individuals with disabilities as the regional chair of the national blind organization in the Netherlands. This was followed by his involvement in the national organization for deafblind people. In the

early 1990's he broadened his participation by becoming active in the European Deafblind Network, in which he was eventually elected as the secretary. Lex worked for EDbN until 2001.

By this time his contributions to the field of deafblindness and disabilities were well established. As a result of his hard work Lex was elected to the board of the European Disability Forum, serving from 1997 through 2011. The World Federation of the Deafblind was founded in 2001 and once again his skills were needed. He was elected as the Secretary General and in 2005 became the President of WFDB.

As a member of the International Disability Alliance, Lex became involved in drafting the UN Convention on the Rights

of Persons with Disabilities. Through his gallant efforts deafblindness is referred to in this important UN Convention.

His international efforts spread further through his involvement as Chair of the International Disability Alliance. In this capacity Lex had the opportunity to address the special session of the UN General Assembly in New York and the Human Rights Council in Geneva on behalf of the International Disability Alliance.

As part of his work as the president of WFDB, Lex was instrumental in the development of various national organizations of persons with deafblindness. He supported the European Deafblind Union and the organization of the African Federation of the Deafblind.

Shirley Rodrigues Maia

is described and admired by her colleagues as "idealistic, extremely professional, hard working and very focused".

From a very young age, dedication to the needs of others was a way of life for Shirley. She began by making baby clothes for poor pregnant women. Now she is known for developing the services for individuals who are deafblind as well as providing training for professionals in the field.

After graduating as a teacher of the deaf she took a special interest in the needs of individuals who were deafblind. She was the co-founder of ADEFAB, a school for deafblind and multi-disabled deaf individuals in Sao Paulo. After her time

at ADEFAB, she and her colleagues provided home based services to individuals with deafblindness. Eventually the group rented a house in the Vila Mariana area of Sao Paulo to house a new school called AHIMSA.

She always wanted to do more and improve the quality of services for deafblind people in Brazil. To achieve this she first set out by broadening her knowledge and skills. Shirley attended Dbl World Conferences and participated in other training opportunities located around the world. With this new knowledge she was motivated to form a network involving educators, families and persons who are deafblind. This network

eventually was called GRUPO Brazil. Her leadership in this organization strengthened services for individuals with deafblindness throughout the country.

Shirley worked directly with the programs but also realized the importance of working with government officials to gain their support. Through these contacts she became widely known throughout the country and was constantly called upon to give lectures and seminars from Amazonia in the north to Rio Grande do Sul in the south; from Bahia in the east to Rondonia and Mato Grosso in the west.

Through her efforts, Sao Paulo city and State now recognize deafblindness with a law that celebrates the last Sunday of November as "The Day of the Deafblind". She is now helping other states in Brazil to follow the example of Sao Paulo.

Shirley is also a skilled fundraiser and has secured government and private funding to promote deafblind services and awareness throughout Brazil.

To top this all off, Shirley continued to focus on her own education which resulted in the recent awarding of a PhD from MacKenzie University.

Dbl is indebted to Shirley and her colleagues at Ahimsa for co-hosting the XV World Conference with only 2 years to prepare.



**Shirley Rodrigues
Maia receives the
Distinguished
Service Award**



Bernadette Kappen receives the Distinguished Service Award

Bernadette Kappen

has a long history of working with and advocating for individuals with deafblindness. Her scope of support ranges from infants and toddlers to adults in retirement as well as for both those with congenital and acquired deafblindness.

Bernadette began her career at the New York Institute for Special Education as the Educational Supervisor for the Deafblind Program. In 1982, she brought her expertise and leadership to the Overbrook School for the Blind in Philadelphia, Pennsylvania, becoming the school's Director in 1991. She established an Early Intervention Program, an Early Childhood Outreach Program serving pre-schoolers in community settings; a Work Experience Program for students ages 16-21, and an International Outreach Program in Asia and Central Europe.

She was the guiding force in helping the parents of young adults with deafblindness establish alternative living and supported employment programs through the creation of the Overbrook Friedlander Programs in 1986, a program that she served as the Executive Director for 2007. In 2008, Bernadette returned to the New York Institute for Special Education as the Director.

In addition to her employment history, she has served on the National Advisory Boards of both the Helen Keller National Center and the American Foundation for the Blind; served on the Journal of Visual Impairment and Blindness (JVIB) editorial board and was a guest editor for a special edition on Deafblindness. Currently she is a member and past president of the Council of Schools for the Blind (COSB), and is an Ex-Officio

member of the American Printing House for the Blind. She is also actively involved in the Association and Rehabilitation of the Blind and Visually Impaired (AER), the Council for Exceptional Children (CEC), and the International Council of Persons with Visual Impairment (ICEVI).

Bernadette has been a member of Dbl for many years and has served on the Management Committee as Vice-President since 2003.

Bernadette's career exemplifies a continuous commitment and concern for quality services for all individuals who are blind, deafblind, or have multiple disabilities. She has earned the respect of professionals throughout the world and more importantly, the respect of those she has spent her life serving—individuals who are deafblind or multiply disabled.

Anne Sullivan awards presented during XV Dbl Conference

Gala Dinner, September 30, 2011

Steven Rothstein, Perkins International President, presented the highly coveted Anne Sullivan award to three highly acclaimed professionals in the field of deafblindness at the XV Dbl World Conference in Sao Paulo Brazil.

The Anne Sullivan award winners were: Isabel Amaral (Portugal), Maria Aparecida Cormedi (Brazil) and Shirley Rodrigues Maia (Brazil). Isabel was the Chair of the Dbl Conference Scientific Committee, while Maria (Nina) and Shirley were Co-Chairs of the Dbl Conference.

Isabel Amaral is presented with the Anne Sullivan award by Steve Rothstein of Perkins International



Shirley Rodrigues Maia (L) and Maria Aparecida (Nina), winners of Anne Sullivan award



**Scenes from the
Gala Dinner XV Dbl
Conference**



Outgoing...



The outgoing Dbl Board



The outgoing Management Committee

What an exciting year this has been!

World Conference

We attended the XV Dbl World Conference in Sao Paulo, Brazil September 26-October 01, 2011. The Conference was a successful event with a thought provoking program and some wonderful social gatherings amongst old and new friends. We wish to thank the hosts Grupo Brasil and ADEFAV for their tremendous efforts. The Secretariat was proud to represent Dbl in the display area at the conference. The new banners were unveiled and the Dbl souvenir pins and flashlight key rings proved to be a must have item. It gave us the opportunity to talk with many of the delegates from far reaching regions of the world. Many existing members renewed their membership and we were pleased to welcome a number of new members to Dbl. We take this opportunity to welcome them to the Dbl family!

Dbl Meetings

During the conference week in Sao Paulo we were pleased to coordinate the meetings for the Dbl Board, Management Committee (ManCom) and the Annual General Meeting. We farewelled the Outgoing Board and thanked them all for their wonderful efforts during the term they served. Without their valuable contributions, the important work of Dbl simply couldn't be accomplished. At the Annual General Meeting the proposal for the new officer positions and Board membership was presented and was accepted with resounding enthusiasm. We are delighted to welcome the elected members to represent their organization or

Network to the Board of Dbl. For many of them it's "welcome back". The experience, knowledge and relationships built over the past four year term with these members and their organizations provides a strong foundation on which to launch into this new phase for Dbl. With several new Board members elected, the new perspectives, personalities and enthusiasm will further strengthen this wonderful organization. We very much look forward to working with the new Board to progress the strategic goals, objectives and key actions of Dbl. The Annual Report and a list of members of the Board is available on the Dbl website and in the Minutes from the Annual General Meeting. We encourage you to take a look at the list and see who you have elected to shape the direction of Dbl for 2012 – 2015.

In particular we wish to congratulate Gill Morbey on her appointment as President of Dbl. Over the years in our term as Secretariat we have worked closely with Gill in developing the Strategic Plan and have established an excellent working relationship which we look forward to continuing. Senses Foundation is immensely proud to be hosting the Dbl Secretariat and we feel privileged to have entered our term under the guidance of past President, William Green. We take this opportunity to wish William a well-deserved retirement from the role he has fulfilled with such enthusiasm and commitment. Dbl is especially lucky that William has agreed to remain on the ManCom in the role of immediate past president which will be of enormous benefit to the ManCom and Board. We also welcome

Carolyn Monaco as one of Dbl's Vice-Presidents and already we are benefitting from the power of her enthusiasm. With the rest of the ManCom members continuing on in their roles we are confident and excited about the work ahead.

Future Meetings

The ManCom will come together in February 2012 in Lille, France to meet with the Local Planning Committee and Scientific Committee for the Dbl European Conference, scheduled for August 2013. We will also have the opportunity to tour the proposed conference venue and surrounding facilities and accommodation options for delegates. The Secretariat is pleased to be working closely with Jacques Souriau and Dominique Spriet to offer our support and to help circulate announcements to Dbl members.

It was agreed at the first meeting of the Incoming Board in Sao Paulo that to progress the work of the Strategic Plan and to give the new Board members the opportunity to get involved in the work of Dbl it would be beneficial to meet in the first part of the new year. The Board will meet in New York in May 2012.

Networks

The Dbl Networks are a vital element of our organization. Much work has been done and is still in progress to further support these Networks to enable them to operate at full capacity and to ensure they are accessible to all. We are pleased to welcome Lucy Drescher from Sense to assist William Green in supporting

the Dbl Networks. Lucy will be the contact point between the Networks, the Board and ManCom and will be guided by William Green to better support the Networks of Dbl.

Membership

In early 2012 we will circulate renewal invoices to members whose membership has expired. We were very pleased with the strong rate of renewal in 2011

and hope we receive a similar or even better response in 2012. As a member of Dbl, you can help spread the word about our organization and encourage your colleagues and people who are interested to support Dbl to become a member. All the information is available on the Dbl website. Alternatively you can email us at secretariat@deafblindinternational.org and we will be happy to assist with any enquiries.

THANK YOU

Elvira Edwards, Secretary Dbl
Bronte Pyett, Secretariat Manager Dbl



Dbl Board Membership announced for 2011-2014

Management Committee

The Management Committee for the 2011-2014 period includes the two elected officers (President and the two Vice Presidents), the Past President, the Information Officer and the Secretary:



Gillian Morbey
President

Sense UK
(Gillian.Morbey@sense.org.uk)



Carolyn Monaco
Vice-President

Canadian Deafblind Association
CANADA
(carolyn.monaco@sympatico.ca)



William Green
Immediate Past President

Lega del Filo d'Oro
ITALY
(green.lfo@usa.net)



Bernadette Kappen
Vice-President

The New York Institute for Special Education
(USA bkappen@nyise.org)



Ton Groot Zwaaftink
Treasurer

Group Royal Dutch Kentalis
NETHERLANDS
(T.GrootZwaaftink@kentalis.nl)



Stan Munroe
Information Officer

Canadian Deafblind Association
CANADA
(munroes@seaside.ns.ca)



Elvira Edwards
Secretary

Senses Foundation
AUSTRALIA
(elvira.edwards@senses.asn.au)

Representing Large Corporate Members



Gillian Morbey
Sense UK
(Gillian.Morbey@sense.org.uk)



Andy Kerr
Sense Scotland UK
(akerr@sense.scotland.org.uk)

Barbara Mason



Perkins School for the Blind USA
(Barbara.Mason@perkins.org)

Dominique Spriet



French Deafblind Consortium FRANCE
(sprietd@aftam.asso.fr)



Michael Karlsson
Resurscenter Mo Gard SWEDEN
(michael.karlsson@mogard.se)

no photo available

Pierre J. Honore
Interfond DENMARK
(pjh.interfond@mail.dk)



Pilar Gomez
ONCE SPAIN
(pgv@once.es)



Rossano Bartoli
Lega del Filo d'Oro ITALY
(info@legadelfilodoro.it)



Sian Tesni
Christian Blind Mission (Christoffel Blindenmission) UK
(siantesni@cbmuk.org.uk)



Ton Groot Zwaaftink
Group Royal Dutch Kentalis NETHERLANDS
(T.GrootZwaaftink@kentalis.nl)



Jutta Wiese
German Deafblind Consortium GERMANY
(jutta.wiese@blindeninstitut.de)

Representing DbI Networks



Andrea Scheele
CHARGE Network University of Education Heidelberg GERMANY
(andrea-wanka@dbicharge.org)



Liz Duncan
Acquired Deafblindness Network UK
(Liz.Duncan@sense.org.uk)



Sabine Kersten
Siblings Network BELGIUM
(siblingsnetwork@gmx.net)



Diana Bonilla
Employment Network GUATEMALA
(comunicacion@fundal.org.gt)



Ricard Lopez
European Deafblind Network SPAIN
(rlopez@sordoceguera.com)

Usher Network Study Group

Member to be appointed email contact:
(secretariat@deafblindinternational.org)

Representing Small Corporate Members



Beatriz Zoppi
Cooperative
Association "Look
with the Heart"
(COOPA)
ARGENTINA
(beazoppi@yahoo.
com.ar)

no photo
available

**Henriette
Hermann Olesen**
Nordic Centre for
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nordicwelfare.org)



Marianne Disch
The National Centre
of Knowledge on
Disability and Social
Psychiatry (ViHS)
DENMARK
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styrelsen.dk)



Cathy Proll
Canadian Deafblind
Association Ontario
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Jackie Brennan
Overbrook School
for the Blind
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Ricard Lopez
Spanish Federation
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- Latin America
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Elvira Edwards
Senses Foundation
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(elvira.edwards@
senses.asn.au)



Koh Poh Kwang
Lighthouse School
SINGAPORE
(kohpohkwang@
lighthouse.edu.sg)



**Bernadette
Kappen**
The New York
Institute for Special
Education USA
(bkappen@nyise.org)

Board Observers

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



International Board for
Education of People with
Visual Impairment (ICEVI)
Lucia Piccione [lpiccione@
arnet.com.ar](mailto:lpiccione@arnet.com.ar)



World Federation of the
Deafblind
Lex Grandia
DENMARK
lex.grandia@mail.dk;
wfdb@wfdb.org



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

- ☐ 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 Zwaartink – 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

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