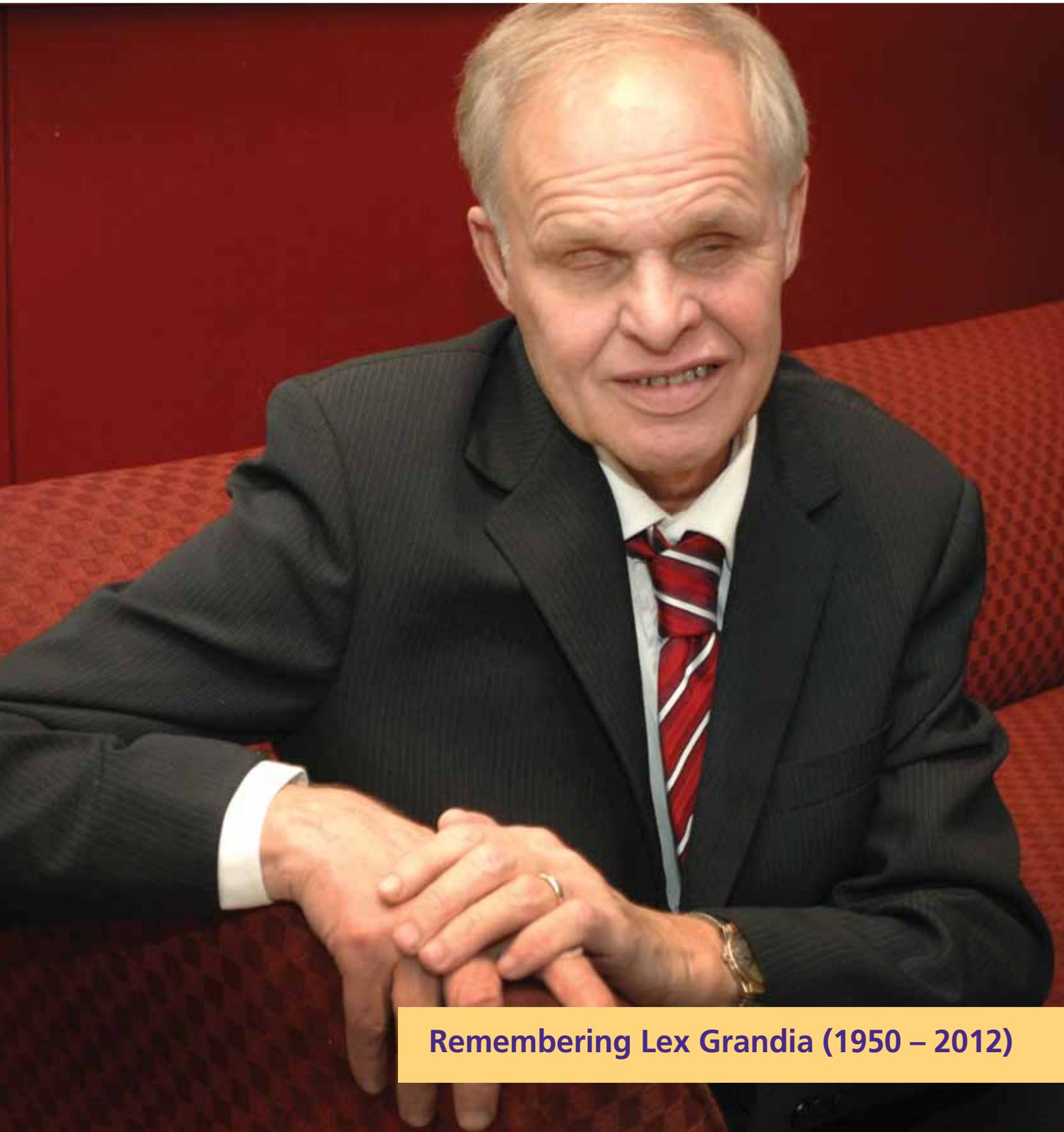


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OF DEAFBLIND
INTERNATIONAL

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Review



Remembering Lex Grandia (1950 – 2012)

A message from the President

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

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

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

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

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Cover: Lex Grandia (1950 – 2012)

Dear Friends and colleagues,

As I write this introduction for our Review I realise what a mixed period we have had. We had our Board and Management committee meetings hosted by Vice President Bernadette Kappen in New York this past May. I think both were successful meetings and it was great to see so many people attending.

We were pleased with the progress on networks. This is much of where DbI activity takes place so it's good to see the energy and commitment. We were interested in the developing arrangements for the European Conference in Lille in 2013. Special thanks to Valerie Taggiasco for the local planning and Jacques Souriau and his team on the scientific committee for the content.

We also had some interesting discussions around social networking, how we manage a 'new world' and the ethical issues that may emerge over time.

We are sad to lose our treasurer Ton Groot Zwaaftink who is leaving Kentalis to take on a more senior role as a CEO. We wish Ton well in his new role and know that he will remain a friend. However we do indeed extend our warmest appreciation to Kentalis who will continue their support and have appointed Frank Kat to take over Ton's role.

Of course the celebrations in New York were marred by the loss of our dear friend



Lex Grandia. Immediate Past President William Green and I attended the funeral in Aalborg on the 28th April. Many people came to pay their respects and although there was much sadness, as you might expect, there was also a sense of celebrating Lex's life and achievements.

I was also recently reminded about Mike Collins, a former past president, as the Latin American Forum on Deafblindness and Multiple Disabilities hosted the second virtual conference dedicated to Mike's memory. I think this is a great idea and a cost effective way to share knowledge, although I don't expect it to ever really fully replace all the benefits that come with personal contact.

We are all looking forward to the ADBN conference in Lund, Sweden in November. The DbI management committee will meet just before the conference allowing a number of us to participate in the event. We are delighted that DbI was able to sponsor some delegates, although we

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recognise that we never manage to do as much as we would like.

As ever this is an eventful and busy period of our organization. A continuing thank you to everyone who works in our field of

deafblindness and all the commitment that's shown every day in lots of different ways.

Kind Regards

Gill Morbey

Editorial

Dear friends of Dbl,

As Information Officer of Dbl and editor of Dbl Review, I have the unique opportunity to inform you about what's happening in the world of deafblindness. It gives me immense pleasure to witness how much this specialized field has advanced in the past 40 + years to help improve the lives of people with this disability throughout so much of the world. While there are so many exciting things happening internationally in this field, it is often a challenge to get reports from people who are doing significant things. Our website (www.deafblindinternational.org) and each edition of this magazine, including this one, attempts to highlight what is just a sample of stimulating programs that are making life better for people with deafblindness.

In keeping with a popular initiative from past editions, we present again several articles of a technical nature. Two articles are from doctoral students working under the supervision of Dr. Marleen Janssen, who heads up the Congenital Deafblind Communication program at the University of Groningen in the Netherlands. We are



pleased to feature an article by Drs Moore and Steer from the University of Newcastle in Australia relating to inclusion of students with deafblindness or multiple disabilities in the public school classroom.

A must read is 'Mélodie's song', a heart warming story about communication through the gift of music. This story could have been right out of Musicophilia – 'Tales of Music and the Brain' by Oliver Sacks (www.randomhouse.ca).

As usual, this edition announces various upcoming conferences: Dbl ADBN in Sweden, November 2012, Dbl European in Lille France, August 2013 and the World Federation of Deafblind Conference in the Philippines, November 2013. An interesting conference reported by Vula and Shirley from Ahima/Grupo Brasil, was the recent Ibero-Latin

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Vice Presidents' reports

Bernadette Kappen reports:



The Strategic Plan has been the driving force for Deafblind International. At the May 2012 Board meeting the members focused on the goal related to fundraising. The members were asked to dream big and think about how additional funds can support the work of Dbl and especially offer increased opportunities for members from developing countries.

The Board divided into small groups and discussed options to raise money. The conversations all focused on an increased awareness of deafblindness along with possible ways to raise money. Ideas ranged from identifying companies that might be interested in our mission, setting up a mechanism for

people to donate in honor of someone, creating options for people to use their mobile phone to donate, writing proposals for specific projects to organizing marathons.

The idea of awareness of Dbl was a constant theme throughout the discussions. One idea was to have a day set aside each year for deafblind awareness. This would be helpful in getting people interested in possibly donating but also help countries promote the needs of people who are deafblind.

The next step will be to write a fundraising plan and circulate it to the Board for comments. Projects will be prioritized and funds sought for these activities. A meeting with chief executive officers from several organizations is

being planned for the fall to put a plan together. At the Board Meeting in May we had fund raising professionals from Changing Our World (www.changingourworld.com), a company that assists organizations in their efforts to raise money, discuss how we might begin a program. Changing Our World will be invited to the fall meeting to assist us with developing the Dbl plan.

This is a very exciting time for Dbl. Our success with fundraising will allow Dbl to grow and reach out to more people around the world. If you have ideas on how we can move ahead with the strategic initiative you can contact Stan Munroe and he will collect these suggestions.

Carolyn Monaco reports:



Here at Dbl our vision "to be the international association which promotes the awareness of deafblindness as a unique disability and to influence for appropriate services for deafblind people around the world" and our purpose "to support professionals, families and people who are deafblind to raise awareness of deafblindness and to support the development of services to enable a good quality of life for deafblind children and adults of all ages" were instrumental

in the development of our 2012 - 2015 strategic plan. This plan continues to drive what we do, how we spend our money and how we measure our success as an organization.

Our strategic plan was reviewed and updated in May 2012 at our Board meeting in New York and is available on the website under the tab "About Dbl". As a result of a well defined Strategic Plan we continue to develop a clear path on where we want to go and effective ways of getting there.

Significant progress has been made in "enhancing our organisational capacity" through the ongoing secretariat and information officer functions as well as increased support to the coordination of our networks. More specific individual membership recruitment plans are being implemented and our efforts to seek recognition of Dbl with the United Nations continue as well.

Thank you to everyone involved!

Memories of Lex Grandia –

International Statesman for Deafblindness

The international world of Deafblindness lost a special friend, colleague and advocate with the passing of Lex Grandia in Norresunby (Aarlborg) Denmark on April 19, 2012. Lex was many things to many people: a theologian, counsellor, husband, father, grandfather, friend, consummate advocate for human rights and a champion of deafblindness.

He was a true international figure and established close friendships with so many people around the world through his Presidency of the World Federation of the Deafblind and long partnership and friendship with members of the Board of Deafblind International.

Lex's legacy will endure for generations through his engaging work at the United Nations to enshrine the human rights for people with deafblindness through the UN Convention on the Rights of Persons with Disabilities.

During a plenary session at the XV Dbi Conference on Deafblindness in Sao Paulo, Brazil (September 2011), Lex discussed



the implications of this convention towards improving the quality of life for persons with disabilities, including his own. During the conference Lex was awarded the Distinguished Service Award, an award presented to an individual who has made a distinguished contribution to services for deafblind people on a national and international level. Lex's plenary and details about his award presentation, including photos were published in Dbi Review, Number 48, January 2012.

Lex had been appointed on April 05 an Officer of Oranje-Nassau by the Dutch Queen. This is the 4th highest order in the Netherlands, Lex's country of birth; which was received posthumously. The Order is a Dutch chivalry order open to "everyone who have earned special merits for society". See en.wikipedia.org/wiki/Order_of_Orange_Nassau.

The funeral for Lex was held April 28 in Norresunby Denmark at Norre Uttrup Kirke followed by a memorial ceremony at Johanneschurch in Utrecht, Netherlands on May 05, 2012.

Dbi extends a special tribute



also to Ann Thestrup, Lex's special life partner. Ann was at his side constantly as a wife and as his communication assistant. While Lex was a very independent professional, Ann was that competent partner supporting and assisting Lex to make his huge contributions to the world of deafblindness.

A few Tributes:

Gill Morbey pays tribute to Lex Grandia, President of the World Federation of the Deafblind:

"Lex was one of the most significant figures in the world of deafblindness. He worked tirelessly all his life for our cause and was a champion of human rights. Lex's warm and generous personality touched everyone he met. We will



all be diminished without him and the world is truly a poorer place without his wisdom, laughter and piano playing.”

We, the WFD President (Colin Allan), WFD Board, WFD Honorary Presidents (Markku Jokkinen and Liisa Kauppinen) and the WFD General Secretariat would like to give our deepest condolences on the passing of Lex Grandia. Lex worked with us all very closely and was one of our strongest and faithful supporters. Together we managed to develop human rights of deaf and deaf-blind people in several ways all over the world. We miss his strong willingness to cooperate and support us, his positive attitude, his warmth and his good sense of humour....

Javier Guemes, on behalf of the European Disability Forum, says: “I would like to express our sincere condolences to Ann,... the rest of Lex’s family... and our friends and colleagues at the World Federation of the Deafblind.



The international movement of people with disabilities has lost one of its prominent leaders and activist. The European movement is therefore very touched and sad by this news. EDF will ensure that we pay tribute to Lex’s legacy by continuing the fight for freedom and equal rights of people with disabilities in Europe and the world.

For further tributes to Lex, including photos and further details about his life, check out the memory book (<http://memorialwebsites.legacy.com/lexgrandia/homepage.aspx>) which is online until May 04, 2013.



Mélodie's Song

This is a story about acquiring language against all odds.

Our Family Bad News

On February 28, 1995, Mélodie was born under very difficult circumstances. With a pre-natal diagnosis of hydrocephalus and Spina Bifida, we knew that life would pose important challenges to our daughter; but we had not been told how serious her condition really was. In fact, the children's hospital where she was born had devastating news for us: Mélodie's case was very rare in its gravity and in the number of conditions.

We were told that Mélodie had no visual cortex whatsoever; in fact most of her brain was absent. What little brain tissue she had was compressed into a thin sheet of brain cells in the periphery of her skull because of a huge intracranial cyst that was taking up most of the space. With no cortex she would never see. We were also told that she had absolutely no responses in a Brainstem Evoked Response Audiometry test (BERA). Even with loud noises (90 db) no brain activity could be detected. She would never hear. The many professionals around the table at the children's hospital said they had not seen this serious a case in 10 years and that not only was she deaf and blind but that she would most likely be in a permanent vegetative state. Mélodie had, we would later learn, more than 20 serious medical conditions, many of which were profoundly debilitating and some of which were even life threatening (e.g. Cerebral Palsy, Syrinx of the upper spine, severe Epilepsy, Osteoporosis, Spina Bifida, Arnold Chiari Syndrome, etc.).

With no hearing and no vision



how could she ever learn to communicate? How could she ever derive any pleasure and satisfaction from life? Would she have any quality of life at all? With all these medical conditions could she even survive? The news was shocking and the best way to describe it would be to compare it to a sudden excruciating jab to the stomach, one so strong that it leaves you absolutely breathless.

No Hearing and No Vision?

While Mélodie was still in her first days and weeks of life in neonatal intensive care, we noticed that she would startle every time she

would hear a piece of equipment begin to beep. We had been told by the doctors that it was totally impossible for Mélodie to hear anything whatsoever. How could she then startle to sounds? We were told that it must be our imagination or because of the movement of air...

At about the same time we noticed that Mélodie had reactions to light that were similar to her reactions to sound. She would startle to a light being turned on and seemed to have some perceptions of objects or people near her because she would react to movement. Over time it was confirmed that in fact Mélodie

had some residual vision, but very little. With no cerebral cortex she obviously had cortical blindness.

After the initial shock subsided, we decided that we would not accept the dire prognosis of the numerous specialists and that we would do all that we could to give our daughter a fighting chance to have the best quality of life possible in her circumstances.

Mélo die's Amazing Progress

Fast forward to 2011! Incredibly enough sixteen years later, Mélo die has developed spoken language and can actually sing some basic songs with melody and words. She has acquired an expressive vocabulary of approximately 50 French words and at least 25 expressions or short phrases (e.g. "la fille à Maman", "brosser les dents", "aller promener"). These words and phrases are not all spoken regularly; some are but others can be used only a few times to reappear in the future or not at all. She almost constantly sings small passages from some of her favourite songs and has even been heard singing "Au clair de la lune" completely from beginning to end on two occasions, one of which was luckily caught on a cell phone video camera. She has surprisingly good pitch and does not sing out of tune.

Amazingly she seems to find it much easier to sing than to speak and most of her words are sung rather than spoken. Most of her singing is akin to echolalia and self-stimulation. However, some of it is clearly used with an intention to communicate ideas, feelings, needs and desires when heard in context. When that is the case small passages or words are sung in 'sound bites' to replace spoken language. At other times she opts to speak rather than to sing.

How is all this possible given the diagnosis and devastating prognosis?

The Solution

The golden rule for us was stimulation. Obviously this applies to vision, hearing, language and physical development. Sign language is obviously the best option for many children. But for Mélo die who has no vision, possesses strong tactile defences and partial paralysis of her arms and hands, sign language was just not an option, not even the hand over hand version. Constantly exposing Mélo die to spoken language was the only solution we could find and this became our priority.

But how do you do that with someone who has very little functional hearing? The solution we found was to expose Mélo die to songs constantly. She listens to songs all night long on her MP3 player and small speakers. Although the volume is low enough that she can still sleep, she listens to the music while sleeping and sings when she wakes up. She listens to songs all day long as well. She does use her MP3 player during the day but Mom, Dad and her brother sing to her most of the time when she is with them, especially when she is being held in their arms on the rocking chair. At school the situation is very similar because the educational staff use songs in abundance. She listens to very little instrumental music because early on she showed a clear preference for songs. She would actually complain when the music was instrumental. She still does! Also, we felt that songs offered her better language stimulation and that was consistent with the acquisition of language, which was our primary objective.

Another important factor is that Mélo die is surrounded not only by songs and spoken language, but also by attention, affection and love. She feels secure, comfortable and happy when she interacts with her family and the staff at school. We have noticed that she only speaks and sings when she feels comfortable and happy: she does not speak or sing to strangers.

Conclusion

Although speaking, singing and songs are obviously not the only solutions to bridging the communication gap between the deafblind child and significant others, it offers a wonderful opportunity to interact and share a common pleasure: communication through the gift of music. Knowing today that music stimulates the brain in amazing ways, namely the language centre, in retrospect it seems a logical choice to have made. We thought at the time that with so little brain tissue it was essential to stimulate her neurons to develop functions and pathways to enable perception and processing of sounds and language. The results speak for themselves and we are convinced that constant exposure to songs enabled our daughter not only to develop her hearing but also to acquire some spoken language and enjoy a quality of life from which she would not otherwise benefit. With children whose deafness originates in the brain, there is hope that stimulation using songs might be as beneficial to them as it was to Mélo die.

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Dynamic assessment of children with deafblindness

Assessing Potentials for Learning During Interaction

Assessment is at the heart of the development of a child who is deafblind. Only by understanding a child's potentials, abilities and needs can one plan an educational program that provides maximum benefit. The important question is, "What is the appropriate way to assess children with deafblindness?"

Previously, the assessment procedures have focused on the use of standardized static tests. The term 'static' refers to a test where the examiner presents items to the child, and records his or her response without any attempt to intervene in order to change, guide, or improve the child's performance. Often the tests do describe the child in general terms; mostly in relation to their relative position in their peer group. These tests do give us an idea of what the child has learned so far and may describe the cognitive limitations of a child. However, they are inadequate in revealing the child's cognitive potentials. When assessment is based on utilizing only standardized static tests, there is a high risk for not recognizing the potential of the child with deafblindness.

To provide insights in the deafblind child's potential

to learn new skills and to give them the opportunity to show their potential, the assessment should focus on providing information about learning processes and teaching strategies that would facilitate learning. This information can only be collected by the inclusion of the child as well as communication partners in the assessment, giving them opportunities for learning experiences. Dr. Jude Nicholas did point this out in his plenary presentation at the XV Dbl Conference and his article published in last Dbl Review (January 2012, volume 48): "Learning in the deafblind child is not intrinsic or individualistic but built up in interactions with the world and people around the child". Many children fail on static tests because of lack of opportunity for learning experiences. But that does not say that they don't have the potential to learn. To provide accurate information about the child's learning ability, change processes, and mediational strategies that



Erika Boers

are responsible for cognitive modifiability, the assessment should be dynamic.

The dynamic assessment model

Dynamic assessment is an assessment model that does take the potential of a person into account (i.e. the ability of a person to learn new skills). Generally defined, dynamic assessment is "an interactive, test - intervene - retest model of psychological and psychoeducational assessment" (Haywood & Lidz, 2007, p. ix). It links assessment with intervention, enabling examiners to move

“Many children fail on static tests because of lack of opportunity for learning experiences. But that does not say that they don't have the potential to learn”

Dynamic Assessment of Children

beyond only testing present levels of performance. In contrast to traditional static assessment, the dynamic assessment model includes: (a) two test periods instead of testing the person only one time (the so-called pretest and retest), and (b) a teaching phase where the person is supported to learn new skills (see figure 1 below).

During the teaching phase the person is offered assistance to

master a task, in interaction with a more capable communication partner. The main differences between normative, static assessment and dynamic assessment can be found in Table 1 below (adapted from Haywood & Lidz, 2007).

In the literature on dynamic assessment, different perspectives are discernible: (a) determining the amount of change demonstrated by a person on a given task in

response to intervention, (b) determining the amount of mediation needed to bring the person to some specified level of competence, (c) determining the extent to which the person benefits from assistance, and (d) the identification of inhibiting factors in learning and processes or means that enable the individual to learn a new task and determination of promising interventions.

Figure 1 General dynamic assessment model



Table 1 Comparison of normative and dynamic assessment approaches

	NORMATIVE ASSESSMENT	DYNAMIC ASSESSMENT
What is compared?	Self with others	Self with self
The process is:	Standardized; the same for everybody	Individualized; responsive to person's learning obstacles
The major question is:	How much has this person already learned? What can he/she do or not do? How does this person's current level of performance compare with others of similar demographics?	How does this person learn in new situations? How, and how much, can learning and performance be improved? What are the obstacles to a more optimal level of competence?
Outcome:	Global estimates of ability, for example IQ or developmental age. Current level of independent functioning.	Learning potential: What is possible with reduced obstacles to learning? How can such obstacles be reduced? How does the individual function with a more experienced interventionist?

Underlying theory

The grounding of this model is to be found in the theory of Vygotsky (Vygotsky, 1978, p. 86) and Feuerstein's Mediated Learning Experience theory (Feuerstein, Rand & Hoffman, 1979; Feuerstein, Rand, Hoffman & Miller, 1980). Vygotsky assumed that children might perform above the limits of their initial capabilities when assisted by a more capable adult. The level of cognitive functioning could be determined by the Zone of Proximal Development (ZPD) which is described as the difference between the actual level of development (what a child can do without help) and the potential level of development (what a child can do with the assistance of a more capable person). It indicates the state of a child's mental development, producing a more comprehensive understanding of the functioning of the child, which is insufficiently represented by the zone of actual development. Feuerstein emphasized the quality of the interaction between child and environment, and developed the theory of Mediated Learning Experience. This concept is defined as a process in which adults interpose themselves between a set of stimuli and the child and modify the stimuli for the child. The mediated learning experience includes several principles, for example the mediation of meaning (focusing the child's attention on what is important in a given context and helping the child to understand its value), the mediation of transcendence (bridging concepts and events beyond the immediate task and inducting abstract ideas), and the mediation of achievement (helping the child to determine effective strategies to reach the goal).

Dynamic assessment with persons who are deafblind

The red thread of dynamic assessment is that children might perform above the limits of their initial capabilities when assisted by a more experienced adult in harmonious interactions. However, it is known that communication with persons who are deafblind, especially those who function at a prelinguistic level – by gestures, vocalizations, eye-gaze etc. – is challenging, even for familiar communication partners (Downing, 1993; Holte et al., 2006; Janssen & Rødbroe, 2007). In this case the question raises whether the competence of the person with deafblindness is constrained by his or her capacity to use the help and support provided by the communication partner or whether it is constrained by the partners' abilities to provide adequate assistance to the person during the assessment. To overcome this problem it is important that dynamic assessment procedures for persons who are deafblind include: the identification of partner behaviors that support the person's communicative competence, and teaching supporting behavior to the adult that interacts with the person during the assessment (Boers, Janssen, Minnaert & Ruijsenaars, in press). The focus of a dynamic assessment procedure for persons who are congenitally deafblind should therefore be threefold:

- 1 Identification of partner behaviors that support the person's communicative competence.
- 2 Positively change the behaviors of the communication partner.
- 3 Assessing the response to the positively changed partner behaviors.

Significant work has already been done in the development

of assessment instruments that can be used with persons who are deafblind (i.e. Andersen & Rødbroe, 2006; Mar & Sall, 1999; Nelson, van Dijk, McDonnell & Thompson, 2002; Rowland, 2004; Stillman, 1978; Stillman & Battle, 1985). Instruments as these can be used for pre- and retesting, as well as identifying inhibiting and promoting factors. Which instrument to use depends on the focus of the assessment and the skills that are assessed. By adding (a) exploration of hypotheses about improving the person's skills, (b) teaching the partners new promoting behavior, and (c) a teaching phase in which the person with deafblindness is taught new skills, the instrument can be transformed to a dynamic assessment procedure.

Research

Dynamic assessment procedures have been applied to different clinical and educational groups, such as children with learning problems, people with intellectual disabilities and children belonging to minority groups (Haywood & Lidz, 2007; Lidz & Elliot, 2000; Tzuriel, 2000). But little is known about dynamic assessment procedures for persons who are deafblind. It is an emerging field that we do need to do more research. At the University of Groningen and Royal Dutch Kentalis in the Netherlands, we took the first step by doing research at the development of a dynamic assessment procedure to assess the ability of a person with congenital deafblindness to learn new interaction and communication skills. This research is done under the guidance of Professor Marleen Janssen.

Similar research studies on dynamic assessment of cognition through interaction are taking place in the Nordic countries in

collaboration with the Nordic Welfare Centre in Denmark (The Nordic Network on Cognition in Deafblindness). However, much more research is needed on this important topic for the deafblind field.

The importance of dynamic assessment

The information dynamic

assessment offers us is essential for the following reasons: it supplies the familiar communication partners with guidelines on how to interact with the child with deafblindness to ensure development; it is providing us with information about what the child is capable of; and, it is offering the child with deafblindness the opportunity to

show what they are capable of. For children with deafblindness, dynamic assessment is the way to assess their abilities to learn; and, most importantly, to let them develop, by learning through interaction. Therefore the appropriate way to assess children with deafblindness is to utilize a dynamic assessment model.

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ADBN 2012 Announces a Pre-conference

Tuesday, November 6, 2012

A good senior life with a combined sight and hearing loss

On occasion of the 9th Deafblind International ADBN Conference in Lund, Sweden, November 7-10, 2012, The Nordic Centre for Welfare and Social Issues will host a pre-conference day on November 6 that will focus on seniors with hearing and vision loss.

A couple of years ago there were ongoing Swedish, Norwegian and Danish projects on seniors with hearing and vision loss. Knowledge on hearing and vision loss among the elderly is something that should reach far beyond the usual circles where

knowledge on hearing and vision loss already exists. Nursing homes, carers, hospitals, labour market, activity centres, families, etc. would also benefit from knowledge of dual sensory impairment such as hearing and vision loss. Ignorance about this issue may force the elderly into isolation and thus cause loneliness, life-style diseases and reduced quality of life. General knowledge of the elderly is at the same time something we would like to communicate to professionals in the field of hearing and vision loss.

- 13:00 – 13:05** Welcome by the Nordic Centre for Welfare and Social Issues
- 13:05 – 13:45** On geriatrics – quality of life, life-style and health of the elderly – TBD
- 13:45 – 14:00** Break
- 14:00 – 14:45** On dementia – Arlene Astell, Stirling University
- 14:45 – 15:15** Coffee break
- 15:15 – 16:15** A good life with dual sensory loss – Liz Duncan & Megan Mann, Sense Scotland
- 16:15 – 16:30** Round-up

The conference is free of charge and the Nordic Centre for Welfare and Social Issues will be serving coffee and cake.

Registration via our website is required in the same way as for courses in Dronninglund.

Final date for registration is October 7 at www.nordicwelfare.org/dbkurser

The conference language will be English for both the pre-conference and the main conference.

Please visit the website for the main conference here: www.skane.se/adbn2012

We invite you to participate and spread the word to other interdisciplinary contacts in your countries.

Conference venue:

Scandic Star Hotel, Glimmervägen 5, SE-224 78 Lund, Sweden

Tel.: +46 46 285 25 00

E-mail: starlund@scandichotels.com



INDEPENDENT DEPENDENCY

LIVING IN TWO REALITIES

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

www.skane/adbn2012

Generating positive interactions in regular school settings

for Australian students who are deafblind or have multiple disabilities



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Abstract

The social participation of students who are deafblind or have multiple disabilities in regular school classrooms and playgrounds is powerfully affected by student behaviour, teacher behaviour, the curriculum, teaching strategies, characteristics of the classroom or playground and school community, as well as the ways these elements combine to produce positive learning environments. Social skills, in addition to academic skills and a student health-related focus provide the three great challenges to successful regular school placement for students who have traditionally been considered too difficult to serve. Some classroom teachers perceive a lack of social and personal skills to be associated with difficulties in peer acceptance and work-related behaviours such as keeping on task or completing tasks with minimal assistance. This paper examines approaches that have proven effective in increasing positive classroom and playground interactions.

“Recent literature on inclusive education (Koster, Nakken, Pijl and van Houten, 2009, p. 135) has emphasized the importance of meeting social needs [of students] more emphatically”. Fully inclusive education occurs when students with disabilities are welcomed

as full-time members in age-appropriate, typical classrooms in their local schools (i.e., the schools they would attend had they not had a disability) and receive the supports necessary to participate in both the academic and social activities of their peers (Correa-Torres, 2008).

Placing students who are deafblind, or who have multiple disabilities in regular education classrooms is, as the late June Downing has asserted, an expression of their “right” to an appropriate education (Downing, 2001; Downing and Peckham-Hardin, 2007). If a “right” can be tentatively defined as an interest embedded in law, the preservation of which is a duty, and the violation of which requires a remedy, then no such “right” currently exists in Australian educational law (Devlin and Devlin, 2004). This circumstance makes the proposition that such students should be educated in regular school settings, both an important goal and a foundation for systems advocacy.

Whether as the result of law, as in the USA, or an important goal, as in Australia, it is not suffice that these students are just “in the classroom” – it is necessary that their attendance results in social participation and real learning.

The paradigm shift from special placement to supported placement in regular school requires that teachers and other educational team members take full advantage of the rich learning environments available to non-disabled students in order to address the specific learning needs of those individuals whose education is their new focus.

Who is considered deafblind or as having multi-sensory educational needs?

Over the years, a variety of terms have been used to describe dual impairment to hearing and sight (Aitken, Buultjens, Clark, Eyre and Pease, 2000). The term “deafblind” replaced “deaf/blind” and “Deaf-Blind” in Britain around 1993 because the use of one word recognised the single nature of the resultant combined sensory disability. In other jurisdictions, deafblindness has been included within a larger (yet still relatively small) group of people labelled severely or multiply disabled, since much of the available educational technology for students who are deafblind was designed for use with students in the larger multiple disability category.

Children who are deafblind are often singled out educationally because impairments of both

sight and hearing require thoughtful and unique educational approaches to enable individuals to attain their fullest potential (Miles, 2000). Indeed, children and young adults who are not just deaf, nor just blind, experience a compounding of learning difficulties due to the combination of the two impairments. Further, the diversity of impairment is so great among those designated deafblind, or dual-sensory impaired or severely multiply disabled, that there is no common baseline from which to begin the education of a “deafblind” child (Clark, 2000).

Education is, of course, one of the most important influences in shaping a person’s life. For this reason, eligibility to receive special supports so education might be accessed is of critical importance. Education expands intellectual and social horizons and establishes social relationships that form the basis for inclusion into adult life (Foreman, 2011). It has been asserted that Australian society is committed to an inclusive ethos (Devlin and Devlin, 2004), therefore all Australian students who are deafblind or have multiple disabilities have a “moral right” to be educated in typical school environments that fully accept them. This means they should be included, wherever possible – in the classroom, the playground and in extracurricular activities with their non-disabled peers – while receiving in addition, the sometimes extensive supports and services they require by virtue of their disabilities.

To achieve these ends, complex service networks and significant resources are often necessary. It is highly important then, that the organisations charged by society with providing quality educational services for all proceed to adopt service eligibility definitions and assessment criteria that address

the often intensive needs of this diverse clientele.

The New South Wales Department of Education and Communities (DEC) has in the past decade, taken steps to redefine those individuals it will accept as deafblind for the purposes of receiving additional resources in school settings. Over time, analysis and debate on the definition as to who might, or might not be considered deafblind resulted in the realisation by Department officials that the long accepted criteria were overly stringent and not particularly accurate. In February 2001, a new definition was adopted, stating:

“Students must have a hearing and vision impairment, both at levels that severely impact on their ability to learn and which result in unique educational needs. In particular, these students will require an alternative means of communication (generally a tactile system) and/or highly specialised technology to facilitate their communication. There must also be evidence that the combined impact of the dual sensory impairment requires an intensive educational provision beyond that provided for students solely with hearing or vision impairment, or severe intellectual disability. In order to qualify for additional assistance in NSW schools, the approval of a Coordinator of Student Counselling and Welfare, together with a Coordinator of Special Education must be sought... before a student can be confirmed as having met these criteria” (Steer, 2001).

Social behaviour and schooling

Social skills, as well as academic skills and a student health-related focus provide the three great challenges to successful regular school placement for students with

multiple disabilities. Generating positive interactions between an individual and student peers, an individual and teachers, and between the school and the families it serves are all-important to the success of an educational placement for a student who is deafblind.

The increasing attempts to successfully integrate into mainstream schooling a broad spectrum of students with disabilities, has generated significant challenges for the regular classroom environment and generic classroom teacher. Students with a complex primary sensory disability (vision or hearing loss) and those who are deafblind, may have associated behaviour problems. They might well experience difficulty in adjusting to life in a regular classroom with its wider variety of teaching-learning factors, especially if they have already experienced a lengthy history of one-to-one early intervention or enrolment in a small, special class program. Of course, if a student has always been part of the regular education environment these sorts of difficulties are substantially reduced.

What is a problem behaviour?

What sets a problem behaviour apart from other behaviours? How is it identified so that it can be dealt with? (Most teachers are sure they recognise it when they see it.) As Charles (1991) has pointed out, for many teachers, problem behaviour means “actions that disrupt, destroy, hurt or infringe upon the rights of others” (p.5). Such behaviour is considered to reduce teacher effectiveness as

well as pleasure in teaching and learning and therefore needs to be minimized, controlled or re-directed.

Conway (1996) presents a scenario much like the following conversation between two teachers, about the threat of having a student with a "severe reputation" in class.

- Teacher A: I'm getting George in my class. I've heard he's a real behaviour problem now and I don't want him. He'll just totally disrupt my class and I won't get everything covered before the next topics test.
- Teacher B: Have you had problems with George before? I didn't realize he'd been in your class.
- Teacher A: Well no, he hasn't. But I've heard he's a major problem for everyone, so of course, he's going to be an issue for me. (M. Steer, April 2002, personal communication).
The scenario points to a number of important issues. These include:
 - (a) the prejudgment of students based on their reputation;
 - (b) an assumption that a problem behaviour will always be one;
 - (c) that it is the student who has the problem, not the behaviour, and that
 - (d) students who interrupt the flow of a teacher's knowledge and performance have a behaviour problem.

For students with significant disabilities in regular classrooms who have behaviour patterns that do not conform to teacher expectations, the issues can be multiple.

Smull and Harrison (1992) have pointed out that, people with severe reputations tell us

more about what is wrong with the school system than what is "wrong" with the individual, and that many individuals with severe reputations have modest, but essential, educational choices that are not currently being made. Crimmins (1994) has expanded this point asserting that, persons with challenging behaviours often experience lives with not only limited choices, but restricted access to their local communities and few meaningful social interactions.

Why do students misbehave?

A number of reasons have been mooted to explain why students with disabilities misbehave, whether they are in regular school or special purpose settings. Foreman (2000, 2011) has suggested three reasons, commonly reported by special educators:

- (a) students do not have sufficient or appropriate skills in their repertoire;
- (b) environmental factors may hinder their ability to learn or apply skills; and
- (c) students are not being sufficiently reinforced for appropriate behaviour.

While these reasons reflect a strong behaviourist perspective, and suggest that students react mainly to external influences, they also point to the importance of skilled teaching being part of the educative process.

Home and school influences

An extensive professional literature discusses the importance of parents and educators of students with dual sensory disabilities working together (Allen, 1995; Turnbull, Turnbull, Erwin, Soodak

and Shogren, 2011). For example, effective early intervention is contingent upon the development of relationships that consider parents to be partners in assessment procedures and in the development of educational programs. Thus, it is vital to ongoing education that teachers appreciate the importance of the student's immediate and extended family (Chen, 1999; Etheridge, 1995). Historically, parents and families of students with dual-sensory disabilities have had to accept inappropriate educational service provision. Many, according to Furneaux (1988), have felt removed from the educational process and frustrated at the displaced social environment of their child. Concerns for appropriate educational provision are, as Allen (1995) has pointed out, inextricably linked with schooling practices and parental involvement with that process.

The challenges for parents, teachers and care-givers of students who are deafblind are many – not the least being the challenge of including the child in the ebb and flow of family and community life (Miles, 2000). A deafblind child does not respond to typical family interactions in ways that might be expected, and as a consequence, parents will often report having been challenged in their efforts to include him or her. For example, instead of having received smiles and lively eye contact from their young child, the parents will have sought more subtle rewards, such as small hand or body movements. Parents will also have had to change their perceptions with regard to typical developmental milestones.

Parents of students who are deafblind or multiple disabled will have expectations of teachers with regard to the education of

their children. In a list of seven expectations, Charles (1991) included two that appear to directly influence the promotion of positive interactions in the regular school classroom. Specifically:

- Parents expect teachers to care about their child as a valued person;
- Some parents expect teachers to discipline their child, because a sense of order and control is necessary, not only at school, but also in the community.

Another perspective emerges in some of the professional literature which suggests that many teachers seem to place responsibility for school conduct of students with special needs, including behaviour problems, squarely on the parents (Croll and Moses, 1995). Patently, it has always been the case that both home and school contribute to the generation of behaviour problems at school. Both need to play a part in addressing the problems and in promoting positive interactions at home and at school. This factor has been tacitly acknowledged in Australian education where schools are required to formulate policies in partnership with families and their community on the premise that positive student behaviour is more likely to result from home, school and community collaboration.

Flexible and creative ways of building successful partnerships with parents need to be considered (Allen, 1995; Guralnick, 2008), and a range of factors require thought prior to commencing any dialogue. Among these important factors are:

- the choice of location for meeting and generating positive relationships (the family home, school or some other setting);
- whether or not the child should be present;
- the availability of transport;

- time constraints, and
- the possibilities of group support.

The one constant factor in whatever the outcome of those choices is time. Generally, neither the teacher nor the parents ever have enough time to satisfy their perceptions of what the child or one another needs. Establishing relationships, talking and listening, observing and demonstrating, and working together all take time. Thus, it is essential that whatever time is necessary to develop positive teacher-parent-family interaction, it is characterised by its quality.

Curriculum

The inclusion of students with severe and multiple disabilities, who themselves represent a wide variety of abilities and needs, presents major questions regarding the development of appropriate curricula and instructional strategies (Goetz, 1995; Foreman, 2011). Providing a quality educational program for students with profound and complex disabilities that is simultaneously functional, inclusive and outcomes orientated, can be an extremely difficult and complicated process for educators and ancillary services personnel (Smith, Gast, Logan, and Jacobs, 2001).

Many schools and programs continue to provide instruction and related supports for these students in a passive manner, focussing on therapy goals rather than on integrated therapy services that facilitate the attainment of social participation and educational goals. In addition, many special educators and ancillary support personnel lack sufficient training, expertise and experience in working with students who have multiple disabilities. As a consequence, the implementation

of curriculum can be the genesis of school-related behavioural problems (Foreman, 2011). These problems can be further exacerbated for students with disabilities who attend regular school settings where curriculum content may be presented in a manner well above their current ability – such as the learning of a spoken language other than English (LOTE) in a primary grade classroom. When customised instructional processes have not been appropriately designed to accommodate student needs and differences, there is little incentive for the deafblind student to participate and learn. A failure cycle is thus initiated, followed by problem behaviour, followed by further failure to learn, and this pattern continues until the student becomes trapped in a negative learning and social spiral from which there is no easy escape.

Neary and Halvorsen (1995) have specified that a fully inclusive curriculum should emphasise the student's social participation as a member of the class, and systematic instruction of the student's individual educational program (IEP) objectives. It is a fundamental premise of this process that new skill, concept and behaviour acquisition occurs within the on-going social context of the typical classroom. Thus, a creative response to the learning of a LOTE in the primary grade classroom may be, for example, that class members learn through social interaction and help-giving, the gestural-tactile language of the student who is deafblind.

Teaching environment and methods

Specific factors that adversely affect positive interaction and social participation include the way that teachers teach. Teachers might

(continued on page 52)

8th Dbl European Conference

August 27-31, 2012, Lille France

Identities and changes

Commonalities across deafblindness.

Learning from each other.

Why this topic?

Life trajectories of deafblind people differ from one person to another. But all of them have to face differing degrees of changes. These changes will relate to aging (transition from childhood through adulthood to old age), family contexts, and to the evolution of their physical conditions (especially when deafness, blindness and other difficulties appear).

These individual changes occur in a social context which is also subject to other changes outside their control including technological, political, economic conditions and the type of knowledge used by professionals. While all these changes require creativity in each individual's life, at the same time they also create vulnerability in their lives including the work of the professionals associated with them.

Lately in Europe, many people involved in Deafblindness (including deafblind people themselves, family members and professionals) had to face huge changes in the organisations they are related to as a result of policy

changes and state decisions. It is really a paradox that this has occurred since the recognition of Deafblindness as a unique disability was recently proclaimed and endorsed by the European Union and various states. In many instances, these changes have resulted in the mixing together of deafblind services with other types of disabilities.

Therefore, the purposes of this European conference is to show and describe the resilience of 'Deafblindness' as a unique disability in spite of these changes and to find ways to promote approaches that will positively affect the lives of deafblind people and their families.

The format of the conference will reflect the idea that deafblind people should be given all the space they need to assert their own identities and perspectives. It should also ensure that all the varied identities related to Deafblindness (persons with congenital or acquired Deafblindness, family members or professionals) will receive focus, with the intent to show how

all these identities are mutually connected and contribute to the building of each individual's identity.

The four themes of the conference:

- **Denial, shame and pride.**

Access to other people's minds and affective involvement. When facing obstacles and processes of change, people with Deafblindness and/or their companions often face feelings of shame. Examples could include for the deafblind person, their feeling of shame for using a mobility stick; for the companion or partner, their feeling of shame for accompanying a congenitally deafblind child that is behaving differently. This feeling of shame is present in all human beings from the beginning of their lives. Shame appears in the contact between the person that feels the shame and the gaze of the others. Conversely, pride can also appear when shame is overcome through a type of relationship that transforms a difficult situation into an achievement. Special attention should be given to the role of support groups, and other types of relationships that facilitate the change from one of shame to one of pride.

- **Empowerment:** The idea here is to look at how the power of making decisions and the knowledge about deafblindness is distributed among the deafblind people and the social

Some members of the Conference Local Planning Committee





world around them: Who knows? Who is the expert? Who makes the decisions? Knowledge is not only on the side of the professional 'experts'. The source of knowledge is rather with both deafblind persons and their various partners; especially the collaboration between these sources of knowledge. The main focus of this session would be to look at how the expertise of Deafblind people can be practically recognised together with how the roles of their partners can be mutually defined in such a way that the agency of Deafblind people is ensured in order for them to "take the floor"

- **Identity and narrativity.** Building the identity. Identity is built everyday by each individual. Several fields of science (sociology, neurology, psychology) describe how human beings achieve their identity in two ways: by constructing the

story of their own lives and by playing with the various roles they can endorse in relation with other peoples' roles. What is it to be deafblind? Is it to be labelled 'deafblind' by experts or is it deciding that "I am Deafblind". One can see him or herself either as a 'congenital seeing and hearing' person in the context of Deafblindness or as a referee in the context of a football match. Identity involves a historical continuity in life and the capacity to play with a

variety of social roles mutually related and also connected with other people's roles. This need for fostering the identity is visible in many deafblind people that like to write or to tell the story of their lives. However, the resilience of these life stories depends a lot on

their being reflected in other people's eyes and actions. Congenital Deafblind people are considerably vulnerable from that point of view.

- **History of Deafblindness and report of the focus group on the commonalities across Deafblindness.** Historically, the word 'deafblind' was first used to describe children who were born deafblind or became deafblind very early in life. Eventually other types of Deafblindness were included under the 'deafblind' category (ie acquired Deafblindness, elderly Deafblindness). However, most of the time, service providers and professionals deal with only one of the two main categories of Deafblindness (Congenital or Acquired) because there are perceived differences in the developmental conditions and in the type of approaches they need. Therefore, it seems very important to describe how the various worlds within Deafblindness developed historically and to demonstrate how much each group can learn from each other and equally contribute to the overall knowledge in the Deafblind field.

The members of the Dbl Conference Scientific Committee:

(back row): Jacques Souriau (France), Ursula Heineman (Austria), Marleen Janssen (The Netherlands), Ole Mortensen (Denmark), Paul Hart (Scotland), Alexis Karacostas (France);
(front row): Mira Tzvetkova (Bulgaria), Linda Eriksson (Sweden)
(missing from photo): Georgia Pappa (Greece)



A new development:

the Kentalis Deafblindness Centre of Excellence in the Netherlands



Chrétienne van der Burg (left) and Trees van Nunen (right)

Royal Dutch Kentalis is a national organization in the Netherlands that has specialized in the diagnosis, care and education of people with impaired hearing or communication for more than 180 years. Kentalis serves children, young people and adults who are deaf, seriously hearing-impaired, or deafblind, as well as people with serious speech and language difficulties. Kentalis has 4500 employees at approximately 85 sites in the Netherlands. There are around 15,000 clients.

Kentalis' expertise goes back many years in the education, care and diagnosis of children and adults with acquired and congenital deafblindness. A merger and major reorganization within Kentalis has led to requirements for a critical evaluation of services for people with deafblindness. This low incidence population, characterized by its complex wide ranging

characteristics, finds itself at a substantial risk within an organization as large as Kentalis. The fragmentation of services, furthermore make it harder to retain expertise specialized for this population. Our aim is to respond more efficiently and effectively to the questions of people with deafblindness by means of a better organization of our services and activities. We believe that A Deafblindness Centre of Excellence is the answer.

Problem analysis

The Danish philosopher Søren Kierkegaard observed that 'Life can only be understood backwards, but it must be lived forwards'. This principle is very relevant when carrying out a problem analysis.

The communal view of deafblindness appears to lose focus because of the broad distribution of clients with deafblindness across the multiple Kentalis organizational units.

Making the knowledge of deafblindness useful in the professional field was hampered for the same reason. Since there was insufficient liaison among the various units involved in providing services to people with deafblindness, a more integrated range of services was unlikely to arise. There was also a need for a clear definition of the target group, because of the risk of failing to identify some clients as being deafblind.

This analysis was the starting point for launching the Kentalis Deafblindness Centre of Excellence. This new Centre is oriented towards a goal in which there is a close link among clients, staff, organizational units and working locations, both within and outside Kentalis. The safeguarding of knowledge about deafblindness is an essential part of this aim.

Objectives of the Deafblindness Centre of Excellence

This Centre brings together existing Kentalis services and activities that are oriented to people with deafblindness and experts in diagnostics, education, treatment, support and scientific research related to deafblindness; erasing differences of vision and attitude among organizational units.

The Deafblindness Centre of Excellence accordingly has the following objectives:

- To apply known effective methods, interventions and innovations currently in practice and to investigate the development of new methods and interventions.
- To respond to individual needs more effectively and efficiently, and in a more integrated way, as viewed from the perspective of a person with deafblindness.
- To improve the match between the demands of

people with deafblindness and the range of services. We offer a well-defined range of services according to an established working method.

How are we to achieve our aims?

The Deafblindness Centre of Excellence will focus on:

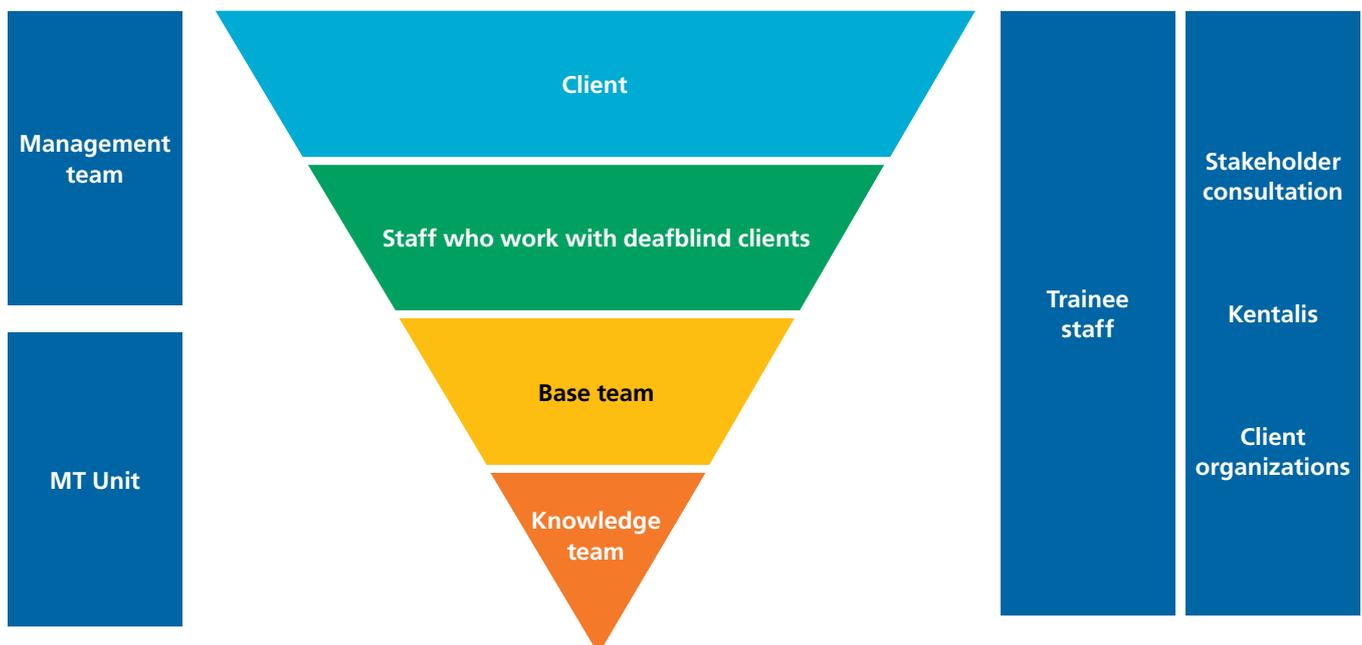
- Achieving transparency and consistency in the range of services for various stages of life.
- Concentrating staff expertise.
- Improving quality of service delivery.
- Encouraging deafblindness knowledge development and the dissemination of that knowledge.
- Forging links with interest groups and other parties that work on behalf of people with deafblindness, both in the Netherlands and abroad.
- Attempting to remove current obstacles that exist in legislation.

Organization structure

The figure below shows the organization structure that was started in January 2012 to achieve the objectives.

Who are the clients? They are children and adults with congenital or acquired deafblindness, who approach Kentalis for support in relation to their needs for accommodation, education, diagnosis, treatment, or counselling.

Who are the staff who will work with the deafblind clients? All Kentalis staff who work with people with deafblindness will be interviewed to ascertain their specific expertise. Employee profiles will be created to determine the allocation of current staff to jobs, departments and working locations within Kentalis. Staff will be selected according to their best fit to the target group (i.e. children or adults with congenital or acquired deafblindness); their special



areas of current responsibility or specific expertise regarding deafblindness. This process will have established a database describing the expertise, products and services currently available within Kentalis.

The base team comprises Centre of Excellence ambassadors who will keep their fellow employees informed about a wide variety of developments. This Kentalis base team with expertise in the field of deafblindness are drawn from all regions in the Netherlands in which Kentalis is present or representative as widely as possible across current education, care and diagnostic services.

The knowledge team comprises experts in the field of deafblindness who are responsible for implementing areas such as research and innovation and development of a system of trained consultants in deafblindness.

How does this affect people with deafblindness?

People with deafblindness who approach Kentalis are given the most appropriate and correct answers to their questions as quickly as

possible. They can be sure of a consistent response, whether related to diagnosis, education, treatment or support. It will be clear to them from the outset of implementing this Centre where their questions can best be answered. They should be confident that the professional (or carer) they deal with is fully qualified and is an equal communication partner; and furthermore that the philosophy and methods used are evidence-based and result from scientific research through close collaboration with the University of Groningen.

Where do we want to go with the Deafblindness Centre of Excellence?

The Deafblindness Centre of Excellence opened on 1 January 2012. We documented our Philosophy of Action as the basis for the centre's methods. The Centre of Excellence endeavours to develop its activities on three interrelated pillars: highly specialized services, research and innovation and consultative services. There are seven basic focuses for attention: diagnostics,

education, rehabilitation, care, safeguarding knowledge, consultation and communication coaches. Our initial emphasis is on refining and firming up the objectives, with subdividing those objectives that are feasible in both the short and the long term. Sharing knowledge and teamwork both have a high priority, not only within Kentalis, but also with other organizations that provide services to people with deafblindness in the Netherlands and abroad. We should also emphasize that clients will also be involved and embedded in further development of the Centre of Excellence.

In closing, we wish to say that the enthusiasm with which Kentalis professionals and clients with deafblindness and their social network are coming together in developing and implementing this Deafblindness Centre will guarantee a high degree of excellence in Kentalis' continued support for people with deafblindness.

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Omissions

We apologise for the omission of references from an article in the last edition (January 2012) Article title: Conference Plenary Presentation: Transition (pages 15-17).

The author had left out references as follows: National Family Association Deaf-blind(NFADB), *Transition and post-school life survey*, August 26, 2008.

Petroff, J. G. (2001) *National Transition follow-up study of youth identified as deafblind: Parent perspectives*. Monmouth OR:NTAC.

The daily life of deafblind people

Nordic Conference 2012

From April 23 through 26 (2012), the Nordic Centre for Welfare and Social Issues hosted a Nordic conference on deafblindness. Some 170 professionals from Denmark, Norway, Sweden, Iceland and Finland gathered in Oslo, Norway for the event. They enjoyed ten plenary speakers and could each pick four of 26 workshops. The main focus of the conference was the everyday life of people with deafblindness in relation to professionalism, visibility and documentation.

The conference was held in mixed Scandinavian tongues and fully interpreted into Icelandic, Finnish and both Swedish and Norwegian Sign Language. In the autumn of 2012, a booklet on the conference will be available from The Nordic Centre for Welfare and Social Issues in Danish only.

Below you can read a few highlights from the conference.

What's in a word?

One of the hot topics recently in the Nordic countries is the term 'deafblindness'. Some people identified as deafblind by the Nordic definition do not identify themselves with the label, as they often have residual hearing and or vision. Losing the rest of their residual senses, rendering them

literally 100% deaf and blind, is their worst nightmare. As Nina Skorge, who has Usher syndrome, put it in a workshop: "When I am called deafblind, I get the same ominous feeling someone with cancer would get if 'welcome to the valley of death' was written at the entrance door to the hospice".

At the same time, using the 'd-word' makes it much easier for these individuals to receive assistance from various social assistance agencies, according to the experience of some professionals in the Nordic countries. These professionals indicate that they must perform a balancing act between offending the people they work for and obtaining the best help for them.

Deafblindness in ICD-11?

Bertil Bjerkan, associate professor at the University of Oslo, pleaded that we need a specific diagnosis for deafblindness. "In the World Health Organization's International Classification of Diseases (ICD), you may find CHARGE, Usher and other syndromes causing deafblindness. However, you will not find deafblindness even though it is a condition which is unique and consistent. A girl of eight years with deafblindness and a man aged eighty with deafblindness have something in common unrelated to the reasons for the deafblindness but related to the impact it has." It is the impact,

Monika Steorn gives a plenary speech on the relationship between pride and shame



Snapshot from the workshop held by the Scandinavian Network on Acquired Deafblindness (SNED)

Bjerkan argued, that should form the basis of the services offered.

Text: Lasse Winther Wehner

Photos: Svein Erik Dahl

Advice from Dr. Jude Nicholas regarding Tactile Communication

If you work with people with congenital deafblindness, you can help support their cognitive development. Here's what Jude Nicholas suggests:

- Assign meaning to the unique bodily/tactile bits of communication they use.
- Start early providing tactile stimulation, and using tactile signs.
- Create a harmonious social interaction.
- Use the tactile sense to create the necessary emotional relationships.
- Learn to understand the relationship between tactile cognition/working memory and language learning.



Empirical research in the field of deafblindness

About the author: Ineke Haakma, (PhD-student University of Groningen, Dept of Special Needs Education and Youth Care), Royal Dutch Kentalis, the Netherlands, I.Haakma@rug.nl

1. The relevance of empirical research in the field of deafblindness

How can we provide people with deafblindness the care and education they deserve and need? How do we establish best practices in the field of deafblindness? Empirical research provides the means to answer such questions. Empirical research is about formulating research questions, generating assumptions and expectations, collecting data and confirming whether or not the assumptions and expectations are valid. The findings of empirical research serve to inform the people in the field (parents, caregivers, teachers, communication partners or practitioners) about what works. However, it is up to the people in the field to decide if, when, how or to what extent he or she will use the empirical findings.

Empirical studies often provide insights into a particular phenomenon, case or situation. For example, people with deafblindness often have additional disabilities, such as disabilities related to motor functioning. Let's say, we

want to figure out if there is a relationship between motor disabilities and problems related to social interactions. We may have all kinds of assumptions of how the two relate. In order to test these assumptions we have to collect data. Once we know the impact of motor problems on social interactions, practitioners can use this information to guide their behavior when trying to improve the social interaction with people who are deafblind.

2. Evidence based practice

As stated, empirical research provides insights in a particular situation. It helps us to figure out why or how something happens. As such, empirical research is also useful to compare practices. Empirical research allows us to evaluate the effectiveness of a method, training or intervention. For instance, a teacher of a special education class wants to know what kind of teaching instruction method he should use. The teacher will preferably use a method which has proven to work, as opposed to a method that has not been tested. The teachers should have the opportunity to choose

practices based on the available evidence. In their search for evidence, teachers can and should make use of empirical findings to determine which practice will be beneficial. The question remains however, how can we judge the findings of an empirical study?

One way to judge the quality of an empirical study is to evaluate the findings in light of the research design. By evaluating the research design we can determine whether or not we find the outcomes of the study convincing. What's important to remember is that there are different designs possible and there are different opinions about the quality of the designs.

3. Randomized controlled trials

According to Odom et al. (2005) research is designed to rule out alternative explanations for both the results of the study and the conclusions that researchers draw. The higher the quality of the research design used, the more confidence we can have in the findings of the study. The randomized control design is often seen as the best design to pinpoint specific causes of phenomena and exclude

Ineke Haakma



other explanations. The design provides multiple opportunities to control for (possible) confounding influences. Therefore it is often called the golden standard of empirical research (Rossi, Lipsey and Freeman, 2004, p. 237)

However, randomized trials tend to rely on a large number of observations. In general, these studies require large groups of participants. This is difficult to accomplish when studying people with deafblindness because it would be very hard to find a large enough group of people with deafblindness who all can participate. Another difficulty with such a study is the heterogeneity of the population. If we want to compare two groups of people, we need to assume that both groups are to some extent alike. We need to conclude that the intervention really has effect, and that the effect is not caused by other factors. People with deafblindness often have additional disabilities. These additional disabilities can possibly have a large effect on their behavior and therefore affect the outcomes of such a study. Outcomes are influenced by additional disabilities such as motor, cognitive or

neurological impairments. For these reasons, conducting randomized control trials in the field of deafblindness is extremely difficult, if not impossible to do.

4. Single case studies

Parker, Davidson and Banda (2007) also note that we cannot use randomized group designs to establish evidence that supports existing and emerging practices in the field of deafblindness, because of the low incidence and heterogeneity of the population. If randomized control trials are so difficult in the field of deafblindness, the question remains whether we can attain the evidence needed to establish best practices in the field of deafblindness. We need to

look at other study designs of which two promising candidates will be described.

4.1. Case study research

The first design is case study research. With this design we can make a detailed, in-depth study of a single subject or a small group. The case study design can be used for multiple purposes. It can be used to foster innovation; to develop new skills; to validate theoretical assumptions; to study rare phenomena and to provide data which can be used as a basis for further research (Barlow, Nock and Hersen, 2009). The use of multiple data sources is a key strength of the case study design. Data sources are for example, interviews, questionnaires and observations. By obtaining and comparing information from different

sources we gain a detailed understanding of that which we study.

4.2. Single subject design

The second design is the single subject design. Single subject designs are used to test the effectiveness of an instruction, training or intervention. Single subject designs are experimental designs, similar to randomized control designs, but on a smaller scale. As such, the single subject design provides greater control possibilities than the case study design. There is no control group; the participant serves as his or her own control (Horner et al., 2005). Behaviour of the participant is measured repeatedly over time (before, during and after intervention). We can use techniques to establish behavioural patterns during the different moments in time. Through comparison of these patterns we are able to discern the effects of a particular intervention. We can generalize the findings by replicating the study

with different participants. This design offers a lot of flexibility and possibilities. The design is flexible because it is easily adaptable to multiple situations. The design makes it possible to monitor the effects of an intervention at different moments in time. We can therefore gain detailed insight into the effect of the intervention on an individual.

5. Criticism on single case studies

Single case study designs have been the subject of critique. An often mentioned criticism is that single case studies only provide concrete, context dependent knowledge (Flyvbjerg, 2006; 2011). Consequently, it is said that findings cannot be generalized on the basis of an individual case. Another disadvantage is said to be the lack of control of the designs. Because of the presence of uncontrolled factors, it is not possible to draw causal conclusions (Barlow, Nock and Hersen, 2009). The last example of critique is that data is often retrospective and subjective. Therefore, the results are more likely to be affected by the impression of the researcher.

Such criticisms are not always justified and often need to be nuanced. First of all, it is stated that case studies produce only

concrete, context-dependent knowledge. However, behavior is almost always dependent on context. For example, Odom et al. (2005) describe that the context in special education is very complex and should always be taken into account. It is therefore difficult to state and answer general questions about whether a practice in special education is effective. Researchers must determine what context and for whom the practice is effective (Odom et al., 2005). Case study research is a perfect method for this purpose because it requires researchers to take the context explicitly into account.

Single case studies also offer ways to ensure generalizability and control. Moreover, the single-subject design provides more opportunities to exercise control compared to the case study design. The single subject design gives us multiple opportunities to replicate findings. In case studies it is harder to exercise control and generalize findings. But even if we cannot control for all possible confounding factors, we can still learn from all the detailed information derived from a particular case.

The final point of criticism is the subjectivity of data collection. We can invalidate this comment, by carefully documenting all the steps of the research process.

“But even if we cannot control for all possible confounding factors, we can still learn from all the detailed information derived from a particular case”

When we explain why we make certain choices, we can provide more transparency in the research process. Other people can verify the choices or, if possible, replicate the study. If we carefully document our choices, others can interpret our findings in light of those choices.

To conclude, single subject studies are suitable to establish evidence based practices (Horner et al., 2005). Moreover, according to Parker, Davidson and Banda (2007) we should use single subject designs to validate the most effective educational and rehabilitation practices in the field of deafblindness.

6. Examples of single case studies

In the field of deafblindness a number of prominent researchers use case studies or single subject designs. These researchers use single case studies to contribute to the knowledge of evidence based practices in the field of deafblindness. The following examples illustrate the range of possible topics which can be addressed using single case studies. Bruce, Godbold and Naponelli-Gold (2004) conducted a case study that involved observation of communicative functions and forms expressed by individuals with deafblindness. Another

example is a study conducted by Vervloed, van Dijk, Knoors and van Dijk (2006). They conducted a case study in which the interaction between a teacher and a deafblind boy was analysed.

There are also numerous single subject studies conducted in the field of deafblindness (Parker, Davidson and Banda, 2007). Janssen, Riksen-Walraven and van Dijk (2003, 2004 and 2006) conducted numerous studies to examine the effects of an intervention program to improve the quality of daily interaction between deafblind children and their educators. Two overviews of literature on single case studies are provided by Parker, Davidson and Banda (2007) and Sigafoos et al. (2008). Parker, Davidson and Banda (2007) conducted a literature study of single subject studies on people who are deafblind. Fifty-five studies were found in the categories: behavioural studies, communication studies, studies on daily living skills and vocational studies. Sigafoos et al. (2008) reviewed intervention studies on teaching augmentative and alternative communication (AAC) to individuals with deafblindness. The purpose of the review was to give an overview of evidence based practice in the design of communication interventions for individuals with sensory impairment.

7. Conclusion

In this article the utility of scientific research is addressed. Scientific research is used for multiple purposes: to discover principles, to test our expectations, to solve problems or to develop best practices. Empirical studies are essential to determine what works best. People in the field (practitioners, caregivers, parents, or teachers) can use this knowledge to make decisions about which course of actions to take.

In this article there are aspects of different research designs highlighted. It is often assumed that randomized control trials are the best research design to provide evidence for what works best. However, single subject studies and case studies are perfectly valid ways to conduct empirical research as well. Compared to the large scale studies, the designs are cost effective and flexible. Furthermore, detailed and systematic single case study research can provide a wealth of insights into mechanisms, relations and behaviors of individuals. Therefore, we should acknowledge the strengths of these designs and use them to establish evidence based practices in the field of deafblindness.

However, we should remember that research is not all about discussing the pros and cons of choosing a

particular methodology. That is only a part of it. Research is about using the methods that will best help answer the research question and choosing a method which fits the context. As Flyvbjerg

(2006) states: "Good social science is problem driven and not methodology driven." As researchers we should do our best to address those problems. It is precisely when we address those problems,

people in the field (parents, teachers, practitioners) and especially that people with deafblindness will benefit most.

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Australia



Mike Steer,
Committee
Member
Australian
Deafblind
Council
(www.deafblind.org.au)
reports:

National DeafBlindness Conference Sydney 2013

The 2013 Australian National Deafblindness Conference will be held in Sydney. The Forsight Foundation for the Deaf and Blind's Board has agreed to convene the event in collaboration with other Service Providers, for example, the Deafblind Association of NSW, Deaf Society, NSW/ACT Guide Dogs' Association, Vision Australia, Royal Institute for Deaf and Blind Children, ABLE Australia and a group of passionate individual supporters. Sponsors are being sought. It is hoped that people who are deafblind, and require financial support will be able to apply for sponsorship in order to participate fully in all aspects of the Conference. The date and specific venue have not yet been set. More information is available at: forsight@bigpond.com

National DeafBlindness Camp, March 2012

Thirty seven Deafblind campers and 53 volunteers attended a very successful 12th Deafblind camp at the beautiful Yarra Junction, an hour and half from Melbourne. Those attending came from New Zealand, Perth, Adelaide, Sydney, Gosford and Victoria state. During the weekend there were activities even though

it rained on Saturday all day. There was a tour to Healesville Sanctuary to see the Australian native animals, then on to a nearby winery. Some campers went bushwalking along the Warburton Trail, to the cafe, on a flying fox and canoeing and of course there was a great deal of social chat. It was great fun and there were plenty of laughs. Staff from Western Australia's Senses organization travelled to Victoria to assist Able Australia staff at this important event.

Let's Connect

Let's Connect is an Able Australia program that aims at providing assertiveness training to people with deafblindness, their families and carers. A national Let's Connect meeting was held in Melbourne on 2nd March, 2012 with delegates attending from Queensland, New South Wales, Victoria, South Australia and Western Australia. A key message from the speakers was that Australians with deafblindness need to join boards, committees and advisory groups to start getting the needs of people with deafblindness heard and understood. There was a motion to establish a facebook site for people with deafblindness to share ideas about the key issues and needs of people with deafblindness in Australia

and also to share experiences about representing people with deafblindness that encourage others to do the same. For further information contact : meredith.prain@ableaustralia.org.au

Ablelink

The national Transport Accident Commission has granted Able Australia in Melbourne, a short term project on "Peer to Peer Braille Training" for the current financial year. Two trainers are deafblind and have received ongoing training from a Braille Teacher on teaching strategies. The trainers are providing Braille training to other deafblind people so that they can have better access to ipad, iphone through Braille displays. There are also other trainers sharing their expertise with ipad or iphone using adaptive applications (larger screen, colour font and many more). This project is the first one of its kind in Australia.

Ablelink has secured two small grants this year called "Peer to Peer training" and "Low vision and braille access to mobile devices" We have been able to buy a range of mobile devices including ipads, iphones and braille displays to facilitate this training.

Some deafblind trainers are teaching braille literacy and braille access through iphone and ipads. Other deafblind

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trainers are teaching how to access ipads and iphones using magnification.

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

Usher/Deafblindness Camp – Western Australia

Senses Foundation is pleased to announce that the First West Australian Deafblindness Camp will be held November 9-11, 2012 at Erin Halliday Recreation Camp, Hillarys, Western Australia. Senses will host a variety of activities over the weekend for people who are deafblind to enjoy: canoeing, archery, swimming, abseiling, flying fox and team building exercises.

For more information contact: karen.wickham@senses.asn.au

NSW Deaf-Blind Community and Helen Keller Day

The Leader of the Opposition in the New South Wales Legislative Council Mr John Robertson (Member for Blacktown) gave a speech to the House on Helen Keller Day with regard to the lack of funding and support for people who are deafblind

in New South Wales. A transcript of this can be read at New South Wales Legislative Council, Hansard, 2011, page 5829. It can also be viewed on line at: <http://www.parliament.nsw.gov.au/prod/parlment/hansart.nsf/V3Key/LA20110915026>

Media Access Australia– Social media for people with a disability

New research and guides released today by blind internet expert Dr Scott Hollier from Media Access Australia (MAA) aim at making Facebook, LinkedIn and Twitter more accessible for people with a disability, to ensure that one in five Australians aren't left behind as social media use becomes more popular. Research conducted overseas in 2011, which measured various social media applications against world accessibility guidelines, found LinkedIn was the most accessible social media platform – with a usability score of just 29%. Facebook scored just 9% and Twitter scored 0, due to every element of its website being inaccessible. Web accessibility refers to the degree to which people with disability can perceive, understand, navigate and interact online.

The report, guides and tip sheets can be found on the Media Access Australia website at <http://www.mediaaccess.org.au/online-media/social-media>

Living Life My Way – Final consultations

Living Life My Way is the NSW Government's

commitment to ensuring people with disability, their family and carers are at the forefront and centre of decision making about the supports and services they use. The State's Minister for Ageing and Disability Services launched the final stage of consultations for the program on Tuesday 24 April 2012.

In his opening address, the Minister declared "Living Life My Way is one of the most important reforms our government has ever embarked on. It will ultimately transform the quality of life for people with disability in NSW." Following the launch there will be over 80 state-wide consultations for people with disability, their families, carers, disability service providers and other key stakeholders. A discussion paper has been developed that details a series of practical options for changing the current NSW disability system to deliver person-centred planning, funding, services and decision supports. Targeted consultations for culturally and linguistically diverse communities and Aboriginal communities will be held later in 2012. More information contact: pcaconsultations@fac.nsw.gov.au

National Disability Research and Development Agenda

Under Australia's National Disability Agreement, governments have committed A\$10 million to disability research and development. Ministers have now endorsed a National

Disability Research and Development Agenda that sets out research directions, principles and priorities. It details particular areas of inquiry for disability-related research and identifies approaches to further the development of this research.

Five broad directions have been identified as priorities:

- Australian disability demographic profile and trend information, including access to social and economic inclusion data;
- Disability related social and economic inclusion research, including a focus on human rights, participation in community life, access to mainstream activities and services, and broader systems change;
- Evaluations, reviews and research to contribute to the evidence base to improve service delivery and support options;
- Analysis of factors that support sector sustainability, sector development and improved organisational capability; and
- Research on the profile, experiences and issues affecting diverse and/or disadvantaged groups of people with disability such as: Aboriginal and Torres Strait Islander communities; people from culturally and linguistically diverse backgrounds; women with disability; and people in regional, rural and remote areas.

Under each of these broad directions the Agenda identifies areas of inquiry which will be priorities for the allocation of research

funding. It is not anticipated that the national funding commitment of \$10 million will cover all the research directions and priorities. The Agenda has been developed with the aim of influencing the direction of research relating to disability across a range of national research initiatives and sectors. One of the first initiatives under the Agenda will be to invite the submission of research proposals. Submissions will need to include information on how the research will be translated into practice and the potential outcomes for people with disability. Contact Information: philippa.angley@nds.org.au

New app increases access to theatre for hearing impaired Australians

A new service from Adelaide-based The Captioning Studio allows patrons to access theatre captions on their iPhone, iPad or iPod Touch in selected venues. The app gives Deaf and hearing impaired theatre goers the freedom to sit in any seat in the theatre to enjoy a captioned performance. Go-Theatrical Mobile can be purchased for \$1.99 from the App Store, allowing patrons to select the captioned performance they're attending from a list of shows. The app means that theatre patrons now have a choice of watching traditional open captions on plasma or LCD displays fixed to the side of the stage, or closed captions on a personal device.

More information is available at: info@mediaaccess.org.au

Online video service brings treatment to children with disabilities

A new Government initiative aims at providing children with hearing or vision impairment living in regional and remote Australia with the ability to talk from home to a specialist. The Commonwealth Minister for Disability Reform and the Parliamentary Secretary for Disabilities and Carers, recently launched Remote Hearing and Vision Services for Children Initiative. The initiative aims at improving health care services for children with hearing and vision impairment living in regional and remote areas in Australia via an online video service. The Federal Government is investing A \$4.9M over three years to deliver this initiative to 125 additional children in regional and remote Australia. This service is supported by the National Broadband Network (NBN), which is currently rolling out high-speed internet access to 93% of Australian homes, schools and businesses. The NBN provides support for services such as these that require fast internet connections, particularly in regional and remote Australia where fast internet access is less common than in urban areas.

The initiative is detailed in a media release (http://www.minister.dbcde.gov.au/media/media_releases/2012/007).

Australia continued

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Defying Adversity Desert Trek



Sharyn Mitchell, who is Deafblind, is about to embark on the challenge of a lifetime, traversing the 1850km Canning Stock Route in remote Western Australia on foot.

In a feat that would demand the most from even able-bodied athletes, the 47-year-old Secret Harbour grandmother and mother of three is preparing to let her feet do the talking in a bid to raise awareness of Usher Syndrome. Sharyn was diagnosed with Usher Syndrome at the age of

17. Her sight has gradually declined to less than five degrees of vision and she had dual cochlear implants in her early 40s. Sharyn is a founding member of the West Australian Usher Syndrome Support Group and continues to be a strong advocate and role model for people living with Usher Syndrome.

Always the intrepid adventurer, Sharyn is pictured above completing her first sky diving jump, she took the plunge at Jurien Bay, Western

Australia in April, 2012 and said that it was: "The scariest most exhilarating experience of my life and I would do it again in a heartbeat! I now have a new ambition - to do it solo one day which involves at least 10 tandem jumps!"

But there are even greater challenges ahead for Sharyn and her team as they prepare to trek hundreds of kilometres of shifting sand dunes, spinifex and deal with snakes and searing heat. The

Canning Stock Route is one of the toughest and most remote tracks in the world. It runs from Halls Creek in the Kimberley region of Western Australia to Wiluna in the mid-west region. With a total distance of around 1,850 km (1,150 miles) it is the



longest historic stock route in the world. The trek is now a popular but challenging four-wheel drive adventure but has rarely been traversed on foot. The track has never before been conquered by a Deafblind woman. Sharyn's Seeing Eye Dog Versace will also be the first service dog to walk the Canning Stock Route. Seeing Eye Dogs Australia (SEDA) is fully supportive of this amazing adventure and commented



that Versace and all Seeing Eye Dogs are exceptionally fit and healthy and that Versace would do well. He is incredibly loyal and so closely bonded with Sharyn that he would follow her to the ends of the earth.

The outback odyssey from Halls Creek to Wiluna will take the team up to 10 weeks, trekking on average 25-30 kilometres per day, crossing some of the world's most inhospitable country. The conditions will be so harsh that Versace will walk only small sections of the route, leaving Sharyn to rely on a shoelace tied to her finger and tethered to another member of the team to help her navigate the track. The women will take turns to pull three specially made trailers each holding 45 litres of water and personal items. They are training three

hours a day in preparation for the gruelling desert trek. "We need to get as fit as we can because it is going to be a huge physical challenge. In some areas the track is rough, narrow and winding, while in others it goes over repeated sand dunes." Sharyn said "the snakes are the things I am most worried about because I won't be able to see them."

Trekking alongside Sharyn (47) and Versace will be Pam (47) Sharyn's sister Lauren (43), Anna (47) and also Greer (40), a senior instructor with Seeing Eye Dogs Australia who will help to ensure Versace's health and safety during the trek. They have a support person Greg Webb, Laurens husband, who will travel ahead, within radio distance of the group in a four wheel drive in case of an emergency and also

to give Versace a ride a few hours a day so he can rest. The support person will also carry the extra water and supplies that the ladies will need; replenished every 4 days as their trekking trailers load is depleted.

Why do such a long and potentially dangerous trek? Apart from the sheer challenge and consequent satisfaction of conquering such a large feat, Sharyn and her dedicated team want to raise awareness and funds to support people living with Usher Syndrome and Dual Sensory Loss. Senses Foundation is fully supporting Sharyn with this venture. For more information regarding the trek, to be updated with their progress and to follow this inspiring journey, go to: <http://defyingadversity.com/>

Australia continued



Left to right: Sharyn Mitchell, Greer Gerson, Anna Bottle, Pam Armstrong, Lauren Mitchell; front: Versace

Brazil

II Virtual Ibero-Latin American Forum on Deafblindness and Multiple Disabilities:

Linking knowledge for inclusion- discovering possibilities and building networks.

In Honor of Michael Collins



Ahimsa (Educational Association for Multiple Impairment) and Grupo Brasil (Deafblind and Multiple Sensory Impairment Network) hosted the 2nd Virtual Ibero-Latin American Forum on Deafblindness and Multiple Disabilities, together with partners: University Center of Ji-Paraná (CEULJI/ULBRA), Lutheran University of Brazil and Perkins International/Lavelle, 28 May to 30 June 2012. 'Linking Knowledge for Inclusion: Discovering Possibilities & Building Networks', the title of the second forum, was in honor of the late Michael Collins, past president of Dbl and Director of Perkins International.

Sixty-five presentations were available to download free of charge to the more than 460 participants who registered from Argentina, Brazil, Chile, Colombia, Ecuador, Mexico and Peru. Each forum was enriched through the exchange of experiences from the participants from the different countries who had the opportunity to express their opinions, problem solve and exchange points of view. All this made it possible to expand our networks and discover new possibilities for connecting together all the knowledge available to improve the quality of life for children, adolescents, adults

and families of people with deafblindness and multiple disabilities.

The themes included: **Education** (Inclusion in Regular School; Guide-interpretation; Intervenors; Co-teaching; Universal Design for Learning; Assistive Technology and Accessible Resources; Orientation and Mobility; Transition to Adulthood and Tactile Communication)

Health (CHARGE Syndrome; Usher Syndrome; Congenital Rubella Syndrome; Pediatric Rehabilitation; Neurological and Cortical causes)

Family (Transition to Adulthood; Collaborative Teams; Associations and Supporting Networks)

Research and experience reports (Education, Family, Culture, Sports, Leisure and Health)

We wish to acknowledge the renown experts who so kindly took the time to prepare and make presentations in the following categories: Tactile Communications: Barbara Miles, Paul Hart, Bernadette van den Tillaart and Aase Endrensen; Transition and Families: Steve Perreault, Joseph Shiroko, Paula Rubiolo, Graciela Ferioli and Aurea Soza; Inclusion: Maria

Bove, Isabel Amaral and Carolyn Monaco; Rubella issues: Stan Munroe; CHARGE Syndrome: Tim Hartshorne and Veronika Bernstein; Pediatric Rehabilitation: Jude Nicholas; Advocacy: Ricard Lopez; Arts and Culture: Gill Morbey; Music: David McCluskey, and Drama (promoting independence and communication): Jon Reid.

We also give our sincere thanks to those who made this a fruitful and rich event: Gloria Gil, Ximena Serpa, Mariela Pacheco, Florencia Trujillo, Marcela Toscano, Marcela Quiroga, Carmen Guerrero, Sandra Polti, Paula Perez, Alejandra Grzona; and our Brazilian colleagues Iolanda Utuari, Susana Araújo, Dalva Rosa Watanabe, Maria Piedade Resende da Costa, Renata Gramani, Sandra Mesquita, Silvia Estrela, Denise Teperine, Marilene Souza, Marcia Lopes and Daniela Forchetti. We also thank the many who presented the practical part with reports on their experiences from all parts of Brazil and other countries in our beloved Latin America. Finally, special thanks to our secretary Ines Igino for all her dedication and patience.

Sincerely
Shirley Rodrigues Maia and Vula Maria Ikonomidis – Forum Organizers

Greek Deafblind Association celebrates 20 years

Greece

Toula Matsa and Georgia Pappa report

Friends and members of the Panhellenic Deafblind Association gathered together for a wonderful evening on May 28, 2012 to celebrate Deafblindness Week and the 20th Anniversary of their association.

The event took place at the Petreza Tower, Spaton-Pikermi region near Athens, honoring the memory of Mike Collins (Director of Hilton Perkins Program International) and Lex Grandia (President of the World Federation of the Deafblind WFDB). Attendees remembered the great contributions by Michael and Lex to the work of the association, as well as the progress that the organization has made over the past 20 years.

Guests were treated to the narration of the folk story 'The Blind and the Hunter'



Anna narrating the folk tale

by Anna Stamatopoulou and a performance by the Coucoubayan Circus, a group of three actresses.

The Panhellenic Deafblind Association was founded in Athens in 1992. This is the only organization in mainland Greece dealing with deafblind people. Its

initial objectives were to create a deafblind centre staffed by specialized personnel that would operate both as an education facility for deafblind children and a vocational unit and residence for adults with deafblindness. While the residential service has not yet been developed, we are pleased to report that the Ministry of Education has established a school and vocational program for young and adolescent deafblind students.



Toula and Alegra assist Ilias

Canada “Embracing the Dragon”

the theme for Canadian 6th Spirit of Intervenor Symposium

The DeafBlind Coalition of Ontario, a network of individuals and organizations dedicated to the sharing of information and promotion of awareness of deafblindness and intervention, hosted their 6th Spirit of Intervenor Symposium March 5th to 7th, 2012 at the Sheraton Parkway Hotel in Richmond Hill, Ontario.

“Embracing the Dragon” was the perfect theme for this year’s symposium. According to the Chinese Zodiac, the year 2012 is the year of the Dragon. In ancient China, the dragon represents emperor and power. Today it is the ultimate auspicious symbol symbolizing success and happiness. Dragons symbolize such character traits as dominance and ambition. They’re driven, unafraid of challenges and willing to take risks. They’re passionate in all they do and they do things in grand

Paul Hart



fashion. There is no one more passionate about their work than an Intervenor.

This Symposium, like previous ones, was specifically designed for Intervenor or those in a supervisory role who work with people with deafblindness. The benefits of these annual symposia include networking, professional development, learning new practical strategies and hearing about the latest information about key issues in the field and becoming more empowered.

This year’s 3 day symposium included a plenary session highlighting the “Embracing the Dragon” theme, a keynote address from Paul Hart (Sense Scotland) titled “The Landscape of Touch” and numerous workshops. Some examples of the 24 workshops included: Personality Dimensions; Embracing and Engaging in a Total Communication

Approach; The Importance of Teaching Healthy Sexuality; Technology: Next Level in Accessibility for the Deafblind; Transitions; and Sensory Exploration Arts (SEA) Explore, Express and Enjoy: Creative Expression Through the Arts. The conference closed with a keynote titled “Taming the Dragon and Relieving Stress with Humour” by popular comedienne and motivational speaker Judy Croon.

The symposium this year drew 300 delegates largely from the Province of Ontario, with some travelling from New Brunswick, Manitoba, British Columbia and Scotland. Participants included students, Intervenor, interpreters, administrators, and teachers involved in deafblindness.

Susan Manahan
DeafBlind Ontario Services

Services for Deafblind Persons in Hong Kong

China

Introduction

In Hong Kong, there is a minority group with dual sensory impairment in the society that is often being neglected or their needs have been misinterpreted in the provision of supportive and rehabilitation services. According to the March 2012 Statistical Report of the Central Registry for Rehabilitation in Hong Kong, 159 people are identified with hearing and visual impairment, or Deafblind. However, this figure may not be reflecting the actual number of people with deafblindness in Hong Kong as the registration is on voluntary basis.

For these deafblind people, their dual sensory loss has created much greater difficulties for their daily living. Unfortunately, Hong Kong Rehabilitation Services does not provide any assistance for this special minority group.

These deafblind people could only receive services offered by the deaf or the blind welfare organizations. Although the number of deafblind persons is small in Hong Kong, their particular needs cannot be ignored; on the contrary, we must address their needs to help them to integrate into the community.

Rehabilitation Services

In view of the service gap, the Hong Kong Society for the Blind (HKSBS) started planning for a rehabilitation programme for deafblind

people in Hong Kong beginning in 1992. From September 1995, this programme has commenced with support from the Hong Kong Community Chest providing rehabilitation training free of charge to people aged 16 and above with dual sensory loss. Living skills training for these clients is provided at the Rehabilitation Centre, the Morning Glory Day Activity Centre cum Hostel of the HKSBS and for those living in the community, according to their individual needs and potential.

HKSBS also joined hands with various professions to develop services in Hong Kong for deafblind persons of all ages. A Deafblind Rehabilitation Programme Advisory Committee was formed in 1999 to start a 'Pilot Project on Training the use of Tactile Signs for Deafblind Persons'. The Advisory Committee members were experienced professionals from Ebenezer New Hope School, Caritas Jockey Club, Lok Yan School, Hong Kong Society for the Deaf and Hong Kong Society for the Blind.

Rehabilitation Training Programmes

Three major aspects of individual training are provided at three different centers of the Hong Kong Society for the Blind to deafblind clients (ages 16 or above) living in the community:

- Tactile sign language is provided by the



Resource Centre for the Deafblind. Other training in communication is also provided.

Resource Centre for the Deafblind

- Orientation & Mobility is provided by the Rehabilitation Centre. Other types of training include home management skills, computer skills and teaching Braille.
- Day care training and residential services are provided by the Morning Glory Day Activity Centre cum Hostel to those deafblind with multiple disabilities or mental challenges.

Resource Centre for the Deafblind

The first-ever Resource Centre for the Deafblind in Hong Kong was established in 2006 to provide supportive

Chinese Tactile Sign Language Training Manuals



China continued

services and consultation to deafblind persons and their family members. The Centre's mandate also included teaching professionals and rehabilitation workers to facilitate the rehabilitation process and strengthen the living skills of these disabled individuals. At the time of writing, the membership of the centre was 137, of which 59 were deafblind persons ranging from ages 9 to 95.

Services provided by the Resource Centre for the Deafblind

The centre provides information on various resource materials to meet the special needs for learning, daily living and social adjustment of deafblind people in the different age groups. These services include: a hotline enquiry service; an adaptive aids consultancy program; community services referral; a resource library service;

educational talks and workshops; community education liaison, various volunteer programmes and public education.

Development of a Chinese Tactile Sign Language (HK)

We are honored to have Rev. Dr. Cyril Axelrod as the Honorary Consultant of our Deafblind Service. Rev. Dr. Cyril Axelrod is deafblind himself. Ever since his visit to the Hong Kong Society for the Blind, he brought his worldwide experience working with deafblind people to foster the development of deafblind services in Hong Kong. With his help the Chinese Tactile Sign Language (HK) was developed since 1993.

Tactile Sign Language is a different modality of communication. Basically, the tactile sign language system in the Chinese language (HK) is based on

the signs used by hearing impaired persons in Hong Kong, with modification from the Makaton (see www.Wikipedia.org/wiki/Makaton) which are signs used for those people with an intellectual disability. The basic parameters of sign formation include handshape movement, location and orientation, with facial expression an optional supplement. The signs are conducted hand-over-hand on a one to one basis.

Standardization of Chinese Tactile Sign Language (HK)

With the valuable experiences gained from the 'Pilot Project on Training the use of Tactile Signs for Deafblind Persons', teaching techniques were published in the first training manual 'Deafblind Training Manual' in 2003. At that time, about 250 vocabularies of Chinese Tactile Sign Language were presented in the first Chinese Tactile Sign Language Vocabulary CD-ROM.

Through consolidating our experience of working with deafblind people over a number of years, we published in 2010 'Communication without Barrier – Deafblind Training Manual' with a DVD. This publication includes a Chinese tactile sign language (HK) vocabulary. This manual aims to increase the understanding of the various needs of deafblind people through interviews with deafblind persons, case studies on training and sharing by professionals working in deafblind services. This informative

5th Anniversary Celebration of the Resource Centre



manual includes resources and equipment available in Hong Kong to help deafblind people integrate in local society. In the DVD, 300 new tactile sign language vocabularies, 50 demo sentences and conversations are presented; as well as, with the approval of Deafblind UK, 'The Deafblind Manual Alphabet'.

The study and development of Chinese Tactile Sign Language (HK) is ongoing, with the intent to build a communication method that is universal to local Chinese deafblind communities.

Professional Development

The centre organizes local and overseas exchanges to enrich the knowledge of our staff as they develop quality deafblind services. Two exchange tours to Taiwan (Tai Chung-2010 and Kaohsiung/Tainan-2012) were recently organized. The Centre staff also attends overseas conferences to share their experiences. A paper titled 'The Development of Chinese Tactile Sign Language in Hong Kong' was presented at the 10th Asia Pacific Congress on Deafness held in Bangkok in August 2009. Exchange activities also included two friendly visits from Japan Deafblind service organizations – 'SMILE' from Osaka (September 2009) and Japan Deafblind Association (January 2011).

Development of Professional Training for the Public

With the advice of Rev. Dr. Cyril Axelrod, a Certificate



Course for Communicator/ Guide for the Deafblind (Level 1 – Basic) was designed in 2010. This course covers such topics as: the definition of deafblindness, communication methods, tactile sign language and orientation and mobility skills. Over 60 students have completed the course and undertaken the assessment. Intermediate and Advanced Level Courses will continue to run to further develop the professional skills of communicator / guides for deafblind people in Hong Kong.

Conclusion

The Hong Kong Society for the Blind has been actively involved in public awareness and providing rehabilitation training and various areas of assistance to the deafblind community in Hong Kong since 1992. The goals of our service

are ultimately to enhance deafblind persons quality of life by: supporting deafblind clients to live independently and maintaining their dignity; enhancing their communication skills, and educating the public to become more aware and accepting of deafblind people. HKSB will continue to work hard to serve deafblind people in whatever ways they need. We intend to continue to share our experiences in Hong Kong in the future.

Tactile communication

Contact Us

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Guatemala **FUNDAL celebrates the inauguration of their new building**



On February 22, 2012, FUNDAL, the Guatemalan Foundation for Deafblind Children, held its inauguration ceremony for the launching of their new building, the Center for Learning and Resources. It is located at 1ª Calle 0-20 Zona 1 de Mixco, Colonia Lomas de Portugal, Carretera Interamericana, Guatemala.

We were honored by the presence of the Mayor of Mixco, Otto Pérez Leal, who gave a speech in which he reaffirmed his support of

**Fundal's
Ribbon Cutting
Ceremony**



Steve Perreault and Diana Bonilla

FUNDAL and his intention to negotiate additional support from the government of Guatemala. We also had the honor of being accompanied by Steve Perreault and Graciela Ferioli, representing

Perkins International. Steve and Graciela were visibly moved by FUNDAL's great achievement and they delivered a message full of joy and encouragement.

This project was made possible thanks to the efforts of Christian Blind Mission (CBM) with the support of the European Union. In this activity, we also had the presence of Sandra Wepler and Diana Acuña from CBM, who directed some words to the guests, and who unveiled the plaques recognizing all the organizations that contributed to this work.

Those present were brought together in the celebration, celebrating with applause, mariachis, catering, wine, and above all, sharing their joy for what this new project represents for our country.

Diana Bonilla
comunicacion@fundal.org.gt



You're hired!

Kenya

Finding work placements in Kenya

When well-qualified deafblind students leave school or college in Kenya many find themselves on the job scrapheap. Maggie Korde, Programme Advisor at Sense International, describes a new scheme to help put this right.

In January 2011 Sense International's East Africa team undertook a planning exercise in Kenya, looking at what services exist to provide vocational training for deafblind students.

There are five schools and colleges in Kenya that accept deafblind students from all over East Africa. The teachers work in difficult conditions and often with very little support. But all believe in the potential of the deafblind children they work with. In many cases, the students arrive at school under-nourished, isolated, neglected and with little confidence. But with the commitment of the teachers and their faith in the students' ability, they often

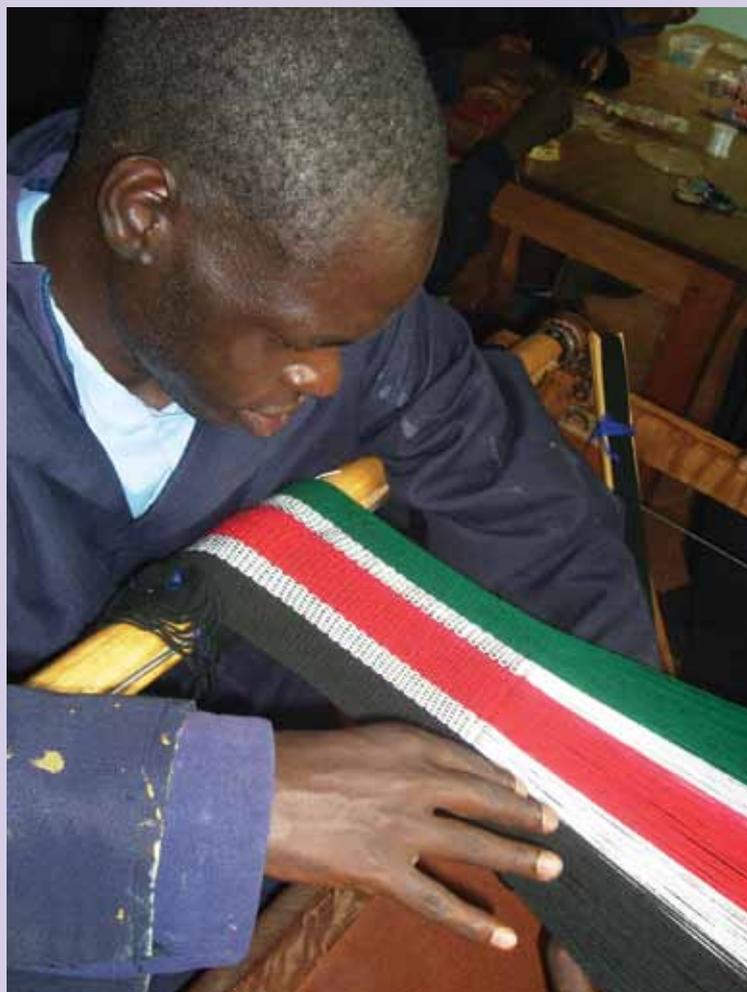
“Students often graduate highly qualified and ready for the workplace”

graduate highly qualified and ready for the workplace.

Unfortunately for the majority of these young people, life after school hasn't provided the opportunities they hoped for. Teachers told us of visiting students a few months after graduation, finding them living in poor conditions, where they were not being properly cared for. Most were suffering from depression and many had other conditions relating to neglect. When staff did find the students working, they were often being exploited and were not being paid what they should.

“It is awful to see them return home to nothing”

One teacher we met at Kerugoya School, Joseph Muturi, told us “It is my job and my honour to teach these young people so that they can meet their full potential and work like everyone else. The problem is that others, including their families, do not see this potential, and it is awful to see them return home to nothing.”



Kenya continued



Our East Africa team set about putting a project together that would address these problems. With the support of two UK businessmen, Sunil Shah and Terry Williams, this is now a reality.

The project's aims over the next three years are:

- 90% of deafblind children will be enrolled in vocational training schools in Kenya, where they will be matched with an Apprentice Trainer (the

current figure is less than 10%)

- 90% of students graduating from vocational training schools in Kenya will be found work placements or will be assisted with a business start up (this is currently less than 10%)
- 300 families or guardians of deafblind children enrolled in vocational training, will take part in school visitations and awareness raising programmes
- 25 families will be trained in family transition and home support in Year One, with this figure increasing according to advocacy efforts in Years Two and Three
- An Advocacy Officer (hired for this project) will take the needs of the schools to district and national government asking them to take on costs associated

with the schooling and vocational training of deafblind children, as they have committed to under recent legislation.

The project also improves the quality of the training and facilities in the five vocational units and in the five other schools with deafblind primary units in the country.

A vocational teacher, at one of Sense International's partner schools, told me how excited he is about ensuring this project is a success, "I just can't believe it. I want to start right now! I have so many ideas – the first thing I want to do is an exhibition of their work in each of the students' communities – we'll show them what they are capable of!"

First printed *Talking Sense*, Summer 2011

“90% of deafblind children will be enrolled in vocational training schools”

The first ever curriculum for early intervention in Romania

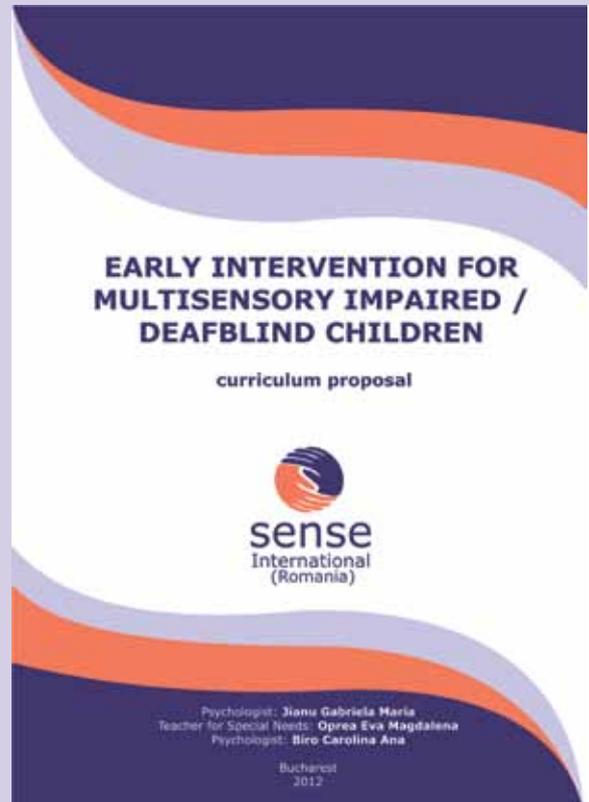
The major consequence of deafblindness leads to the necessity for intervention as early as possible in the development of the child. The involvement of an early intervention specialist and different specialised services has implications for the family. The work of the early intervention specialist with the multisensory impaired child involves one-to-one activities, the aim of which is to reach maximum potential for the child with this disability.

After numerous meetings, the Curriculum for the Provision of Early Intervention Services has been finalised. It is a complex document, developed by professionals who are both national trainers in the field of deafblindness and early intervention specialists - Gabriela Jianu, Eva Oprea and Carolina Biro, as authors. Mihaela Moldovan, Stela Todea and Andrea Hathazi have contributed as consultants. The curriculum,

covering such themes as: Communication, Sensory and Cognitive Education, Orientation, Mobility and General Motor Development and Emotional and Social Development, is a precious instrument to be used by current and future early intervention specialists in Romania. It has been submitted to the Ministry of Education, with the purpose to be accredited as part of national legislation in the field of deafblindness.

The curriculum has been developed for specialist teachers in the field of deafblindness involved in early intervention activities with children from 0 – 3 years old. However, the suggestions in this curriculum can be of great assistance for parents as well as for all persons involved in the educational process of multisensory impaired children.

We are proud to say that this is the first ever document designed and published in



Romania for the benefit of early intervention workers and parents working with babies and very young children with this disability.

Eva Oprea



Gabriela Jianu



Carolina Biro



Ireland

Deafblind Ireland

Ges Roulstone reports:

Deafblind Ireland held its 3rd annual conference on Saturday 25 February 2012 at the campus of the National University of Ireland in Maynooth, County Kildare. The conference title was "Building Bridges"



and focused on the need in Ireland to develop stronger links between professionals, families and deafblind people themselves.

DbI president Gill Morbey made this her first international engagement since becoming President in 2011 and spoke with great energy and commitment from her dual perspective as a mother of a deafblind son and CEO of a large organisation providing services to deafblind people and their families.

She was followed by Megan Mann of Sense UK who delivered one of her stimulating and engaging lectures on communication. The conference also heard presentations from Irish professionals working in



the field of deafblindness: Dierdre Leech and Heather Coulson.

The conference ended with an impressive presentation from deafblind pianist and music teacher Orla O'Sullivan.

The conference gave Deafblind Ireland the opportunity to launch Ireland's first professional course in deafblindness. This course, aimed at improving the skills and insights of different professional groups, will start this spring (2012) and will run on a modular basis over 5 weekends throughout the year, at the University in Maynooth.

Ges Roulstone
Chair of Trustees
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First Announcement

10th Helen Keller World Conference (HKWC) and 4th World Federation of Deafblind (WFDB) General Assembly 2013

This represents the first announcement and invitation to attend the 10th HKWC and 4th WFDB General Assembly planned for the Manila area, Philippines, October/November 2013.

We are at this time in conversations with hotels in the Manila area about costs and other details etc. We will have further information about date, venue, accommodations, conference fees and program for this world conference in our 2nd announcement.

The meetings of the General Assembly are open and consist of deafblind representatives representing the national members of WFDB, as per constitution article 5.

Information about nominations and nomination forms for the different positions in WFDB will be sent out in later announcements. Applications and motions to be considered by the General Assembly must be received by Executive Council at least twelve (12) months before

the date of the General Assembly. The agenda and all relevant documents related to the General Assembly will be sent to all members by the Secretary General at least four (4) months before the date of the meeting.

We welcome you all to the 10th HKWC and the 4th WFDB General Assembly, 2013.

Best regards
Geir Jensen
Secretary General WFDB
fndb@fndb.no

Shelter from the storm

A support network for mothers with acquired deafblindness is offering a group of women a safe place to share their concerns and grow in confidence. Else Marie Jensen and Anette Rud Joergense from Denmark, who are consultants for people with acquired deafblindness, explain how it works.

Nina, a young mother with two small children, has Usher 2. Since 2007, she has taken part in a network group with four other mothers with severe hearing and vision impairments. 'If I didn't have the network group I would only be able to talk to professionals like you', says Nina. 'That means the world to me and I couldn't live without it. It's nice to be with people who feel the same

way I do.'

Through our work as consultants we were often asked: 'How do women with acquired deafblindness cope with their roles as mothers, wives and colleagues?' We didn't have an answer to this so we set up a network group. At first, the women met frequently to get to know each other better; now they meet every three months and communicate regularly by email.

Several of the women describe the group as a turning point in their lives. 'After I met these other women I certainly feel less lonesome,' says one. 'I feel empowered by the sense of belonging. It's nice. I feel a sense of security knowing that others are in the same situation.'

A breathing space

In other social situations, the women have to use a lot of energy to explain their situation to other people. And many times it doesn't actually help. Because how can other people really understand their situation? In the group, the communication is on their terms. Everyone knows what the others need. So they can relax, and some of them feel that, in the group, they can be themselves without simply focussing on sight and hearing.

Nina says: 'Being in the group is a relief and a great breathing space. When I go home afterwards, I can tackle my hard everyday life. Not an impossible life, but a hard one, and then I know that we'll see each other again



“...some of them feel that, in the group, they can be themselves without simply focussing on sight and hearing”

soon and share experiences.’

The five mothers learn from each other – which gives some of them more courage and self-confidence. When someone hears what another woman can do, then she thinks, ‘I can also do that’.

‘Another thing I’ve learnt from the women in the group is their optimism, which I admire very much,’ says Nina. ‘Time and again, I think about it in my everyday life. If they can manage, then so can I.’

Themes in the network group

In the group, the women talk about many different problems related to living with a hearing and vision impairment. For example, some find it difficult to tell other people about their disability. They are afraid of other people’s reaction.

At one meeting, ‘Helen’ talked about her fears of meeting the parents in her daughter’s new school. The teacher wanted each parent to introduce themselves and Helen wanted to tell them about her vision and hearing problems. She needed the other women’s advice to prepare her introduction, because it is hard for her to explain her problems to strangers. ‘How will they look

on me when I have revealed my secret?’ she asked.

That started a useful discussion where each person described their difficulties in telling others about themselves. They all know this feeling.

It is also important to say that the women are at different stages of adjusting to their disability. These differences also encourage dialogue in the group so that the women learn from one another. Before the school meeting, some group members emailed Helen to offer her support – and then she was able to talk about it at the group afterwards. Strong bonds are formed between the women

The role of the professionals

In the networking group all the members are equal, and our role is to facilitate the group process. At first we were responsible, together with the group members, for setting the framework of the meetings, but increasingly the women take on this role themselves.

After one meeting, one of the group members texted me: ‘I never thought, that I should be so lucky and participate in such a good group. I feel safe when I’m together with the group, even though sometimes I cry and sometimes I laugh.’

Some facts about the group

- The youngest woman is 35 and the oldest 50.
- Two of the women have small children.
- Most are diagnosed with Usher 2.
- One woman uses sign language, although she can communicate with speech if the conditions are right.
- Some have known their diagnosis for many years, others were diagnosed more recently. .
- Three members have a disability pension, two have a part-time job, working between 20-25 hours a week.

Else Marie Jensen and Anette Rud Joergense,
Consultants, Centre for Døve, Åbyhøj, Denmark.
For more information contact emj@cfid.dk; www.cfid.dk

‘No one knows what my everyday life is like and how much energy I spend on picking up my children. Not even my husband knows that. He understands a lot – but not 100%, and neither do you professionals or my friends. It’s much easier in the network group. In the networkgroup we know how each other feels. The other women in the group don’t need long explanations but just nod and say: I know how you feel, when I’m telling about situations from my everyday life.’ (Nina 36 years)

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Acquired Deafblind Network (ADBN)

Liz Duncan reports:

The ADBN Co-ordinating group met at the end of March 2012 to continue planning for the Conference in Lund Sweden, November 7-10, 2012. Our main task was to review the workshop abstracts submitted and decide which ones would be accepted.

We had an amazing number of high quality submissions (50), the highest ever for this conference. Since only 30 places were available, some hard decisions were required. Consequently, because of the quality of the submissions and the range of subjects offered, the group made the radical decision to alter the programme to enable 36 different workshops to be held. Since some of the abstracts submitted complemented the planned plenary sessions, we have made changes where it was possible to enable different presenters to work together within plenary presentations.

The Coordinating group is also looking at ways of encouraging more networking, both during the Conference and outside Conference times. There will be some new ideas presented at the Conference, but we are also very keen to hear from anyone who has ideas about this, or who wants to do something, especially outside Conference times.

Perhaps you have some new ideas about work within Acquired Deafblindness that you want to explore with someone from another country, or you would like to know who is working on a particular topic! If so, please do get in contact with the Network



via myself or any member of the coordinating group.

And on the subject of the Coordinating group, there have been several changes to the group over the last 18 months, so I thought I should advise who we are.

Liz Duncan, Chair – UK; Else Marie Svingen – Norway; Else Marie Jensen – Denmark; Henrik Brink – Sweden (Henrik is leading the local planning team for the conference); Christine Aktouche – France; Chrétienne van der Burg – The Netherlands and Kees Kuyper – The Netherlands

We all work within Acquired Deafblindness, but have different experiences and work roles, which means that we can bring lots of different knowledge and understanding to the network – or at least we hope so!

We hope to meet some of you in Lund In November.

**Liz Duncan, Chair, ADBN
Coordinating Group
Liz.Duncan@sense.org.uk**



Future of the communication network

The group discussed the history of the Network and the impact of the fact that Jacques Souriau, Inger Rodbroe and Ton Visser are no longer connected to an organization because of their retirements.

The group agreed that from the beginning, the strength and impact from our network on the field of congenital deafblindness has been through the development of knowledge, including creating theoretical frameworks with regard to communication with persons with congenital deafblindness. Everyone agreed that these have had direct implications for our daily practical work. Reading literature, analyzing video's and inviting experts from outside our field to discuss perspectives and concepts with them have been the main activities of our group.

Having said that, we decided to return to our roots and original strength - that of developing knowledge with clear practical implications for daily practice; continuing to study and further clarifying our perspectives and concepts while analyzing video's. This renewed focus means that some of the activities we started to do or to think about for the future (i.e. organizing conferences, implementing courses, etc.) will not be continued. In line with these discussions, the Network

Communication Network

Ton Visser reports on some of the discussions from the Dbl Communication Network meeting, March 21-24, 2012

will concentrate on the following activities.

Masters Degree Program

The Network group agreed that organizing a high standard Masters Degree Program in Congenital Deafblind Communication through the University of Groningen will remain as one of the main priorities. This initiative forces the continuation of discussions about theoretical frameworks and concepts. Furthermore, it allows many other people the opportunity to study these concepts and expand upon them through preparing their Masters theses.

Supporting the Alumni Network

An Alumni Network has been set up for all students who have finished their Masters in Congenital Deafblind Communication at the University Groningen. At their first meeting on March 22, the Alumni Network defined their purposes and how to achieve their goals. I will mention a few of them: to bring new developments and theories to their working organizations; to stay in close contact with the University of Groningen; to organize and contribute to various seminars and pre-conferences/seminars, etc. The Alumni members organized a very impressive seminar with a lecture from Prof. H.J.M. Hermans, who will be one of the plenary speakers at the Dbl European conference in Lille next year.

Publishing a new book

We are planning to produce a new 'state of the art' book which will

be an update of the 4 books on Communication and Congenital Deafblindness previously published. We hope to do this in cooperation with the Nordic Centre for Welfare and Social Issues in Denmark. In this new book we will try to make insights from the Congenital Deafblindness field more available to the other disability fields, hence the title 'Learning from Persons with Congenital Deafblindness'. We learned at the meeting that some people had problems ordering one or more of 4 books mentioned before. Please contact Ton Visser if you are continuing to have problems ordering these books.

Developing an open access journal

Another part of the meeting included discussion about producing an 'Open Access Journal'. This part of the meeting was very well prepared by Ineke Haakma, PhD student at Groningen University under the supervision of Marleen Janssen. Ineke has agreed to work further on this project based on her investigations to date about these types of journals. We intend to have the first edition prepared before the Conference in Lille next August..

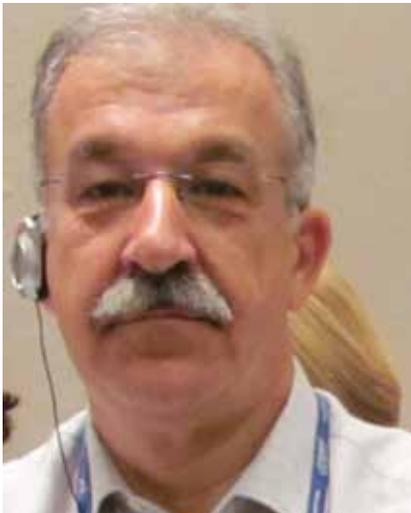
The Network will continue to focus over the the next period on the content of the new book. Please do not hesitate to contact us if anyone wishes more information, has any questions or would like to provide any comments. On behalf of the members of our network, I remain:
Ton Visser
asmvisser1948@gmail.com



European Deafblind Network (EDbN)

Ricard Lopez reports:

EDbN is the European network of organizations of deafblind people, parents, relatives and professionals. In 2011, the EDbN has been able to have a strong impact on important areas related to deafblindness and disabilities in Europe. Examples are listed as follows:



European Disability Forum (EDF)

We are part of a group of experts on the European Union Structural Funds. This is beneficial because it means we have some influence on its budgets and management (for the period 2014 to 2020), and are able to acquire knowledge and establish relationships. We participated in various seminars about accessibility. As members of EDF we have experience in many subjects at the European level.

European Platform of Deafness, Hard of Hearing and Deafblindness

We have become involved in the creation of this platform, which will offer us closer relationships with colleagues in this area with access to high quality information. It will also provide us with direct access to the Disability Intergroup of the European Parliament giving us greater lobbying strength. All

of these reasons give us cause to celebrate.

European Deafblind Union – Agreement of understanding.

We are looking forward to working more closely with our colleagues within EDbU.

World Confederation of Parents of Deafblind Persons – Agreement of understanding

The preferential agreement with the recently created Confederation of parents is another reason to celebrate 2011.

EDbN is being revealed as an excellent working tool for our collective workings at the European level.

rlopez@sordoceguera.com

CHARGE Network Andrea Wanka reports:

This is a short update on what has happened since our last report. As the CHARGE Network representative to the Dbl Board, I was pleased to attend the meeting in New York, May 4-5, 2012. Many strategic aspects were talked about during this meeting, including our Network's plan to host a preconference on CHARGE Syndrome in advance of the European Dbl conference in Lille, August 2013. A task group consisting of Martha Majors, Gail Deuce and myself will speak about the details for this event during this summer. We hope that we

can make this happen! We have already some thoughts about the content, but as we are not used to planning conferences, we must keep the formal aspects and questions in mind. If members of the Network or others have any ideas to share with us for this preconference, please let us know. If anyone is interested in joining the conference and in particular contributing with a presentation, please contact the Network through this email: andrea-wanka@dbicharge.org. Those interested in becoming a member of our network contact us through



this email. For your information, the website (www.dbicharge.org) is still a work in progress.

Contact information:
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Yoga: Lead us from darkness to light

Do you hear with only your ears? Do you see with only your eyes?

How can you chant a mantra if you can't hear? How can you practice yoga if you can't see?

These are the types of questions I asked myself before attending a yoga class for the blind and deaf. Bente Ramsing invited me to her yoga class in Copenhagen in February of 2012. The moment I stepped into her classroom I got a little nervous. Why was I nervous?

It was just yoga. I practice it. I teach it. What was the big deal? I realized that I had never been around a deafblind person before; when was the last time I was around a 'disabled' person? – it was the unknown that was getting to me. This wasn't going to be just any yoga class. I was going to be practicing alongside someone who couldn't see me or hear me. My limited, scared little brain couldn't fathom it.

As I got into a simple crossed-legged position on my mat, my thoughts continued to go on and on. What was this class going to be like? How was it going to feel practicing next to a blind and deaf person? How was she going to know what to do? Could she feel my presence? Was she scared? How would someone like me address her? Communicate with her?

The ninety-minute class started with a short meditation – all of our eyes closed, all of us in the dark. I was right next to Bente's student, who sat next to her interpreter. Bente sweetly led us through a series of sun salutations, standing and sitting poses until we found our way into final resting pose. I experimented a few times by closing my eyes during a vinyasa – trying to feel if only a tiny magnitude of what this other student could be feeling,

experiencing. Have you ever closed your eyes during your practice? What happens to your balance? What happens to your mind? Sometimes it's scary, overwhelming and sometimes it can take you to a place of surrender and expansion of an unknown warm vastness wrapping its arms all around you in all the right places.

The class ran so smoothly. There were no unusual interruptions, there were no outbursts; there were just a few instances when I became aware of the soft muffled sound of moving hands – fingers coming together, motioning, creating a silent language. It was Bente communicating with the interpreter and her student. They used tactile sign language. It blew my mind. My heart softened. My mind humbled. My Universe increased in size.

Sign for yoga

I realized that Bente had invited me into a new world. This is her world where all students regardless of blindness or deafness were seen as individuals. She delicately instructed all of us (there were other non disabled students in the class) to find our own potential. Bente, with her soft tone, her open heart and her gentle guidance invited us into an essence of yoga, an essence of oneness, no matter if we could see it or if we could hear it.



When Bente Met Ella

Bente Ramsing, who has been working with deafblind people for twenty-five years, became a certified yoga teacher 1½ years ago for the sole purpose of wanting to share this practice with the deafblind community:

“A couple of years ago I was working on a project in Nepal. There was a school for deafblind children. I wanted to see how they were teaching – we found that the students there were learning yoga and practicing every morning. I noticed that those children’s bodies were much better than the Danish deafblind children’s bodies. I knew then that I wanted to bring this back to Denmark.”

Upon getting her teaching certification, Bente put an advertisement in a deafblind magazine offering yoga teaching. She received one response. This one response came from Ella Shaeffer who is 69 years old. Before reading Bente’s article, Ella said she knew nothing about yoga, yet she wanted to practice because she wanted to do exercise, but didn’t know how:

“I wanted to practice yoga because my body was very stiff. I should have started practicing long before, but I could not find an interpreter. I started yoga because I wanted to feel my muscles and my body.”

Ella and Bente

I asked Ella how her body was feeling now that she had been practicing for several months:

“My body has changed a lot. I’m not 100% without problems, but my body

has changed a lot for the better. In the beginning, it felt nearly impossible to do postures, but it slowly got better and better. I used to go to a chiropractor, but it didn’t really help. I feel a lot better than before. I feel and stretch my muscles like I never have before and the breathing helps a lot.”

Bente says that Ella’s posture has gotten so much better and that her heart area is much more open. She said that every time Ella leaves the class, she is shining. I have to agree. Ella was all smiles and beaming at the end of class.

To help Ella get a feel for what is happening, Bente has created two ‘new’ yoga signs. She said she created two of them so far. She draws a smiley mouth on the back of one of Ella’s shoulders to let her know she’s doing the pose perfectly. She’ll also gently scratch on the back of one of Ella’s shoulders to let her know when the class is laughing.

It was obvious to me that perhaps yoga isn’t an option available to most people who are deafblind. I asked Ella what she thought about this: *“This is new for deafblind people. Many of them wouldn’t be open to this or they don’t know about it. A lot of them are scared to try new things. It’s just the way it has been.”*

And, what about teaching to deafblind? Bente said that it isn’t very common for people to teach yoga to people who are deafblind. This is something new; as teacher you would have to get very close to the student; it can be a matter of



overcoming a lot of fear.

Bente said she dreams of starting a new revolution – to bring people together in society no matter who they are:

“If you meet someone like Ella, it’s hard to understand how she lives or what she is all about. You don’t know how to go up and say hello, but it is possible to find the courage. It’s important to remember that when she, or other people like Ella, are on the yoga mat, they’re no different from you or me.”

You don’t need eyesight to see the light, and you don’t need hearing to listen to its sweet, supreme guidance. Thank you Bente, thank you so much.

Tanya Lee Markul
Yoga writer for the
Elephant Journal
www.elephantjournal.com

Bente Ramsing – Consultant,
The Centre for Deafblindness
and Hearing Impairment,
Aalborg, Denmark (Bente.
Ramsing@hotmail.com)

“You don’t need eyesight to see the light, and you don’t need hearing to listen to its sweet, supreme guidance”

(continued from page 17)

not be able to compete with the impact of television or interactive videos, but they can ensure that they have:

- fully prepared and planned lessons;
- variety and structure in their lessons, and
- strategies to make the lesson content interesting and engaging.

In a 1991 study of State of Victoria teachers (Lovegrove, Lewis and Burman, 1991), the investigators studying effective classroom discipline found that students identified the following characteristics in their preferred (best) teachers:

- presented information in ways that could be understood by the student;
- had pleasant personalities;
- treated students as individuals, and
- delivered content in a format that was interesting to students.

These characteristics reflect the important links between social and academic focal areas.

Communication

Students with complex disabilities may not have full access to, or full control of, the multiple means by which the majority of students in regular schools communicate; that is, through facial expression, speech, body language and print. Biklen (1993) and Crossley (1992) highlight the tendency for teachers, parents and ancillary personnel to assume that when individuals demonstrate minimal communication skills, they have little or nothing to say.

Simply stated, communication is the exchange of a message between a sender and a receiver in a manner which enables the intended message to be

understood (Butterfield and Arthur, 1995). Communication therefore requires form, content, a reason and a purpose. Stremel and Schutz (1995) have proposed that any definition of functional communication must consider the bio-ecology of the individual and include all aspects of his or her social system. They propose that among the numerous aspects that comprise functional communication, the following concepts are essential:

- that it is interactive;
- that it mediates subsequent events;
- that it can be used effectively in everyday settings with adults, children and peers;
- that it achieves material and social outcomes, and
- that it progresses to higher levels of efficiency and effectiveness.

When communication is unconventional and/or difficult to interpret, adaptations are necessary to ensure consistency of response across team members. To provide greater partner responsiveness and enhance positive interaction, Mirenda (1999) has advocated the development and use of a gesture dictionary, while Downing (1999) has emphasized the importance of enhancing the social environment, and in particular, taking advantage of naturally occurring opportunities within the classroom.

In the classroom

The physical features of classrooms exert an important influence on teacher and student behaviour. Classrooms that are poorly maintained and present few stimulating features fail to create an environment in which students are encouraged to learn. This bareness and disregard can be

observed in some secondary school classrooms. By way of contrast, some early childhood and primary classrooms are so over-decorated and visually stimulating that students can become preoccupied with sensation. For some students who are deafblind or have multiple disabilities, such a busy environment may exacerbate distractibility and subsequent inattention.

Room layout can also affect management of student behaviour. Where a student requires considerable space in a room to manoeuvre a wheelchair, for example, the individual's needs might well determine room layout for all members of the class. Some twenty years ago, research by Merrett and Wheldall (1990) indicated that rows of single desks in a classroom may actually reduce behavioural disruption and increase on-task time at primary and secondary levels. It would be interesting to compare such findings with the present-day preference for group seating which is commonly seen in primary school classrooms and open-plan secondary education settings.

Daily schedules

Timetabling can present difficulties or give support in managing classroom behaviour. The streaming and grading of subject timetables in secondary schools is a case in point. Some timetables in regular schools generate difficulties for students with mobility restrictions that prevent timely movement from class to class. In addition, students with severe or multiple disabilities often become fatigued as the school day progresses, and can therefore find it difficult to maintain their concentration in afternoon classes. Teachers may misinterpret this inattention as a problem behaviour

when, in fact, the problem is inappropriate timetabling.

Effective management

There are obvious benefits to the increased inclusion of students with varied and complex disabilities in regular school environments. Indeed, researchers have found that inclusion is beneficial not only to the students with disabilities, but also to regular classmates who are not disabled (Downing and Peckham-Harding, 2007). Among the benefits that have been reported are the students' increased opportunities to form friendships and enhance social relationships with their age peers. Kennedy and Itkonen (1994) found that regular class participation by students with severe and multiple disabilities significantly increased their social contact with typically developing children. Classroom peers were found to account for 48% of social interactions with age peers during the year. More recent studies have observed some of these interactions to continue outside the classroom, suggesting that students act on opportunity and interest in generalising social skills beyond the initial context and setting (Correa-Torres, 2008).

A number of strategies which relate to classroom management have been discussed in papers reviewing best practice for optimising the social participation and learning of students with significant special needs (Moeller and Ishii-Jordan, 1996; Moller and Danermark, 2007). Foreman (2011) notes these strategies to include:

- consistent structure, routine and predictability;
- explicit rules, co-constructed where possible with student input;

- variety of teaching approaches and techniques (for example, contract, project approaches);
- addressing all learning modes (haptic, aural, visual);
- high expectations;
- classroom atmosphere conducive to learning, active participation and the building of trusting relationships;
- positive reinforcement;
- reward systems in place (using both internal and external motivators);
- continuous evaluation (traditional and authentic);
- multisensory approaches to engagement (teaching);
- small group and co-operative group work;
- opportunities for frequent interaction, and
- connection between topic, student interests, experiences and community (p.232).

Importantly, these strategies reflect good classroom management practice regardless of whether any student requires unique support and resources.

The extent of teacher preparation for each class has an important effect on student behaviour during lessons. If there are a number of hard-to-serve students in a particular class, there is need to ensure that adequate and appropriate activities are prepared for each. This is particularly the case if the students are to perform tasks that differ from those assigned to the majority of students in the class.

The ways in which teachers communicate with students also affects, for better or worse, lesson preparation and student behaviour. One of the secrets of successful teacher-student performance in regular school

classrooms is to ensure that teacher preparation for lessons is thorough and that good management plans are in place to cover total student participation throughout the duration of the lesson (Foreman, 2011).

In conclusion

This brief article has focussed on the importance of developing positive social interactions within regular school classrooms. Together with learning (academic) skills, social participation is imperative if the student with severe or multiple disabilities is to maintain, and enjoy, regular school placement. Social and behavioural problems are likely to occur at any time and in any class; they are not the exclusive province of students with special needs.

Students who are deafblind are often rejected by regular class teachers and students because they do not have the interpersonal and work-related skills expected of their class peers. A variety of approaches can be used to address the development of social participation and positive interaction skills. These include specific behaviour management programs, cognitive and metacognitive strategies, social skills programs, cooperative learning methods and friendship-peer support programs.

Social participation depends on interaction, and as Foreman (2011) has pointed out, interaction is a two-way process, so the development of social skills should not focus merely on the student with severe or multiple disabilities, but also on his non-disabled peers, the class teacher and aide, and ultimately on his school community.

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Dbi Membership

Deafblind International (Dbi), formerly called the International Association of Educators of Deafblind Persons (IAEDB) was founded by educators in the 1960's who recognized the value of regularly sharing information and ideas about deafblind education. Today, Dbi brings together deafblind people, families and professionals from 37 countries around the world to support the development of services for deafblind people. As deafblindness is a low incidence disability, international networking and the sharing of information is essential to the development of quality services for deafblind people. A key to this is membership.

Dbi offers 3 types of memberships: corporate, individual and library.

The general benefit offered to all members is knowing that you are part of an international organisation promoting the awareness of deafblindness as a unique disability and influencing services for deafblind people around the world. All memberships give access to up to date information through the website (www.deafblindinternational.org), biannual editions of Dbi Review, participating in Dbi Networks, opportunities to attend and participate in world and regional conferences, connect with professionals in the field as well as deafblind people and family members.

Corporate memberships provide an opportunity to contribute to the decision making process of Dbi. Representatives from this

membership category may be nominated for any of the executive offices and be nominated to sit on the Management Committee and Board. There are three tiers of corporate membership (large, small and mini), depending on the size of the organization and the membership fee paid. Further details about Dbi membership, including cost and benefits can be viewed on the Dbi website.

How to become a member?

You can join online at: <http://www.deafblindinternational.org/membership.html> or contact the Dbi Secretariat (secretariat@deafblindinternational.org) for further information. Check Dbi out on Facebook (www.facebook.com/dbiint) or Twitter: @DeafblindInt

Editorial (continued from page 3)

American virtual conference on Deafblindness and Multiple Disabilities which allowed over 460 individuals to link online to participate in this event over a period of 5 weeks. Is this type of event, very successful according to Vula and Shirley, a harbinger for future conferences?

Once again it is a treat to hear about activities from regions not regularly reporting such as Hong Kong and Greece. But there is much much more in this edition than my brief remarks about the content.

Finally, I must reflect on the recent loss of Lex Grandia, one of the giants of the deafblind world, who left us much too soon. Lex will

be missed by everyone through his incredible humanity, intelligence, humour, musical gifts and inspirational words of wisdom. This edition of Dbi Review is dedicated to the memory of Lex Grandia, 1950-2012.

Respectfully,
Stan Munroe,
Information Officer Dbi, July 2012

William Green, past President of Dbl

Recognized for his many years of dedication to deafblindness

Deafblind International is taking an opportunity in this edition of Dbl Review to acknowledge Dbl immediate Past President William Green for his long standing contributions to the field of deafblindness and to Dbl.

William's career in the field of deafblindness extends back almost 40 years; to the time when children with rubella syndrome were entering the educational system in the middle 1970's.

His curriculum vitae indicates that his first foray working with sensory disabled individuals was in Oslo Norway in 1973 when he worked as a House father in a Home for the Deaf. Several years after that (1976), he headed up a National Study on the needs of deafblind people in Norway; which led eventually to participating on the State National Team dealing with numerous awareness, training and program development activities.

William, ever so wishing to become fluent in another working language, left Norway in 1981

seeking the language of love in France. With his experience in deafblindness gained in Norway, he became a welcome asset to the Special Educational Centre for Deafblindness in Poitiers, France where he was involved in staff training and adult and family services.

By 1988, the romantic language of France fell victim to the lure of the latin way of life; Italy was now the next adventure in William's march through Europe with his multi-linguistic focus. It was his passion for deafblindness and the desire to improve the lives of people with this disability that took William this time to Osimo Italy and the Lega del Filo D'Oro, where he has been on staff and in consulting roles to the present day.

Throughout William's career, he has been involved in one way or another with Dbl or as it was once named IAEDB, the International Association for the Education of Persons with Deafblindness, beginning in the early 1980's. He's participated in all the International and European



Conferences, as a speaker or member of the planning and Scientific Committees in the last 30 years. William has been a member of the International Executive and Management Committee's since the early 1980's. He has participated in strategic planning and the nominating committee at various times. William was elected as Dbl Vice President in 1999 and became President in 2003 and served two terms until 2011.

In addition to Dbl activities, William has participated in numerous conferences in Europe and around the world; speaking on a wide variety of important issues related to deafblind people, including: Quality of Life, Volunteerism, Employment; Decision making; Ethics; Communication; Elderly issues, etc. These are but a representative sample of the key activities of William over these almost four decades of work dedicated to deafblind people.

The following are words of tribute from three individuals who have known William through most





of his career:

Rodney Clark, former CEO Sense UK and Secretary Dbl:

"William's professional growth during this time was prodigious, and the once rather laid-back young man turned into an effective statutory fundraiser, a very effective creator of new projects and programmes and a singularly successful organiser of national and international seminars and conferences, too many to mention. I well remember the Helen Keller Conference on the Adriatic Coast, a difficult operation to mount at the best of times, when deafblind people, their interpreters and guides would descend from the four corners of the earth with a near inexhaustible list of needs that required meeting if they were to get anything from the event. Everything about this

conference had been organised down to the last detail and William seemed to be ubiquitous, appearing whenever needed, and always there with the right word or action. And in addition to the efficiency of the event, William also exuded warmth and a welcome for which we have all loved him for many years."

Tony Best, former CEO

Sense UK: "So it was absolutely right, when Dbl created 'networks' in 1990s, that William was put in charge of them. He was exactly right for that job as he was so generous with all his knowledge and contacts. He was able to pass on all kinds of information, ideas and people's details to help colleagues develop their services and improve their practice. He has an instinct for creating connections by noticing when people have

similar interests, and loves being able to help people by putting people in touch, and sharing what he thinks they can use. Creating and nurturing networks has been a really strong feature of Dbl over the past ten years, and this is largely due to William's talent and contribution."

Gilliam Morbey, current CEO Sense UK and President of Dbl:

"I am quite sure that William would say he owes a great deal to the world of deafblindness. I can't imagine how many countries William has been to or the number of institutions and deafblind people he has met. William would say he has been privileged but I think we know there has been personal sacrifice along the way and we are lucky to have William as a driving force in our deafblind community."

A busy and productive year already!

DbI Meetings

The DbI Management Committee was pleased to visit France, February 10-13, earlier this year. It was a wonderful opportunity to meet with the Local Planning Committee and Scientific Committee for the DbI European Conference, scheduled for August 2013 in the wonderful town of Lille. A tour of the conference facilities and the chance to talk through the progress for the conference preparations instilled great confidence in us that this conference will be particularly special and a significant event for DbI. We congratulate all the committee members involved and will keep the DbI members informed of conference announcements and important information as it becomes available.

Sr. Bernadette Wynne (HKNC) touring DbI Board members



Elvira and Bronte in front of Place du Général de Gaulle, Lille, France

Just a few short months following France, we had the great pleasure of meeting with the DbI Board and Management Committee in New York. The New York Institute for Special Education (NYISE - www.nyise.org) in the Bronx and the Helen Keller National Centre for Deaf-Blind Youths and Adults (HKNC - www.hknc.org) on Long Island were kind enough to host the ManCom, Board and General Meetings, May 03- 06.

Twenty five Board members travelled to New York from Argentina (2), Australia (3), Canada (4), Germany (1), Norway

(1), Denmark (2), Sweden (1), USA (3), Guatemala (1), UK (1), Italy (1), Spain (3), Netherlands (1), and France (1) to participate in these meetings. With such a great number of Board members in attendance, we were able to pool our experience and achieve a significant amount of work for DbI. The Strategic Plan has provided the framework for the goals ahead and with the enthusiasm displayed by the Board members; we look forward to accomplishing many of these goals in the near future.

DbI was most grateful for the hospitality offered by staff at HKNC (Nancy O'Donnell, Bernie Wynne and Allison Burroughs) who toured the participants through the Center where we met some of the clients and staff. We were also pleased to take the opportunity to inform HKNC staff about the workings of DbI.

We give a huge thank you also to Vice President Bernadette Kappen for her exceptional help in the lead up to our meetings and for hosting the participants at NYISE.

Farewell Lex Grandia

It was with great sadness and a heavy heart we learned of the passing of Lex Grandia. In New York, the DbI Board commenced the meetings with a Minute silence as

DbI Board at Helen Kellen National Center, May 2012



DbI Mancom in Lille France, February 2012





Gill Morbey (right) thanks HKNC tour organizer Allison Burroughs



Treasurer Ton and President Gillian at Dbl Annual Meeting, May 5, 2012

a mark of our respect for Lex. The Board signed a card on behalf of Dbl as a whole and this along with the many heartfelt messages sent to the Secretariat from members have been sent to his family.

ADBN Conference

Momentum is gaining as the ADBN Conference in Lund, Sweden is fast approaching. We are pleased to circulate conference announcements and important news via the Dbl website and emails to members. We encourage

you to register for the conference and check out the preliminary program online at www.skane.se/adbn2012. The Dbl Management Committee will meet to host their meetings in Lund immediately prior to the conference and the Secretariat looks forward to representing Dbl at the conference where people can join or renew as a member and catch up on all things Dbl.

Membership

Following the conference in Sao Paulo, we were pleased to

welcome/welcome back members from Australia, Canada, Croatia, Denmark, Spain, Finland, UK, Guatemala, The Netherlands, Austria, Portugal, Japan, USA, Norway, Ireland, Spain and New Zealand. As a member of Dbl, you can help spread the word about our organization and encourage your colleagues and people who are interested in Dbl to become a member. All the information is available on the Dbl website www.deafblindinternational.org. Alternatively you can email us at secretariat@deafblindinternational.org and we will be happy to assist with any enquiries.

**Thank you
Elvira Edwards and Bronte Pyett,
Dbl Secretariat
Proudly managed by
Senses Foundation Inc.**

Joint Meeting Dbl Mancom and European Conference Planning Group, Lille France, Feb 2012



DbI Board Membership 2011-2015

Management Committee

The Management Committee for the 2011-2015 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
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William Green
Immediate Past President

Lega del Filo d'Oro
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Bernadette Kappen
Vice-President

The New York Institute for Special
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Elvira Edwards
Secretary

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

Board Observers

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

International Council for Education of
People with Visual Impairment
Contact: Dr. M.N.G. Mani
Email: sqicevi@vsnl.net
Website: www.icevi.org

World Federation of the Deafblind
Contact: geir.jensen@fndb.no
website: www.wfdb.org

Representing Large Corporate Members



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



Michael Karlsson
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