



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

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

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A message from the President

Dear Friends and colleagues,

Our last meetings of Management Committee (ManCom) and Board were held in Bucharest, Romania, the site of the 16th DbI World conference, in May, 2015. We also set time aside for our 2014 AGM. Highlighting all these sessions was the announcement of the results of our four year nominations process. Some changes occurred around the Board, including past Vice President Carolyn Monaco moving to a position where she will continue to take an active lead in the DbI strategy, and the welcoming of Frank Kat as the new Vice President. Frank will pair his new role with the Treasurer position on ManCom. At the time of writing, our Secretary Matthew Wittorff is still organising us into our new Board and ManCom functions. I much prefer to say that the status of our organization is really one of evolution rather than revolution. A complete list of the 2015-2019 Board and Executive membership is found on the DbI website.

There is still some work to do around Networks and of course we are planning for the next European conference in Denmark in 2017. There was quite a lot of business that emerged from the first meeting of the new Board but I guess some of the key themes remain around encouraging younger members and representatives



from a greater diversity of backgrounds and regions. This is an ongoing challenge given the financial constraints we all face.

One of the highlights of our meetings and indeed the conference itself was the strengthening of our partnership with the World Federation of Deafblind (WFDB). We had a joint meeting in Bucharest which made for a wonderful opportunity to renew friendships and discuss collaboration. It was also wonderful to have WFDB members attend and present at the conference.

You will read more about the conference in this and future editions of this magazine. But we were delighted that around 400 delegates attended from over 40 countries. There was a good pace to the conference and a number of people commented on how inclusive the event felt. The programme content was excellent with some truly new and interesting ideas. If I may give a 'plug' to my own organisation, we were so pleased that Cristiana Salomie from Sense

International Romania was presented with the DbI Lifetime Achievement Award. We were saddened of course that Joe Morrissey was not there to collect his Award. He is sadly missed.

So we head into the next four years of our strategy with plenty of work ahead, and as usual, demonstrating much energy and commitment.

It was fantastic to be reminded of the fantastic work undertaken by our friends and colleagues, and although meetings and conferences are tiring, I think we all leave with a sense of renewed faith in the service we are doing.

Kind Regards
Gill Morbey, President

Editorial

Welcome to the 55th Edition of DbI Review. Once again we're starting off with emphasis on the recent DbI World Conference hosted by Sense International in beautiful Bucharest Romania. Several articles regarding the conference include Gill Morbey's welcoming address, Tony Best's remarks about the program, and an article outlining the day to day plenaries supplemented by a number of photos. DbI 16 indeed was a spirited conference from start to finish. The Bucharest location really helped to encourage participation from Eastern Europe. I anticipate that the next edition will feature several papers from the conference.

Further to conferences, I wish to bring attention to a wonderful plenary from the November 2014 ADBN Conference in Belfast: Paul Hart's sensitive 'Pursuing Happiness through Trust, Relationships and Communication'. Paul's conclusion in this plenary



suggests that one can either choose to see the challenges of the variety of human differences or choose to see the miracle of human differences; by choosing the latter, one can develop more connections and hence become richer human beings.

Marian Waanders-Westman from the Netherlands submitted a very interesting article (based on her book) about the value of scent in the support of individuals with deafblindness. This paper furthers the discussion about the significance of the (little discussed) sense of smell which helps persons

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Bernadette M. Kappen reports:



Networking, learning and sharing were the highlights for me at the World Conference in Bucharest, May 25-30, 2015. The program provided a wonderful environment to re-energize and work harder on behalf of individuals who are deafblind. The workshops were outstanding and so many new

people were presenting their work. The special nature of DbI comes out when people who work in the field of deafblindness come together. People are focused on the same issue... supporting people who are deafblind. We don't have to explain ourselves – we understand. People connect easily and at the end of the week, you have the opportunity to meet so many wonderful people. I don't believe any other field is quite like the field of deafblindness.

The Conference was very special because of the interactions with members from The World Federation of the Deafblind. The ManCom members had an opportunity to meet with the WFDB members and share ideas for future

meetings. The Board learned about work going on to train interpreters to work with people who are deafblind.

A goal of DbI is to partner with other groups to increase awareness about deafblindness. I think we are on the way to expanding in this area.

I feel especially honored to have been able to work with the Awards Committee to review the nominations of six outstanding individuals who received awards at the Conference. These are leaders who have demonstrated outstanding skills in promoting the needs of people who are deafblind.

Bernadette M. Kappen

Frank Kat reports:



I have been honoured in the recent election with becoming a DbI Vice President. Along with retaining the position of Treasurer, I am pleased to continue collaborating towards the organization achieving its goals.

I wish to take the opportunity to speak about children. Every child is born with the same rights – to food, water, a safe childhood and an education. When I look at children, I see many differences; differences

in talents and behaviour. One child is curious, while another is shy. One may be proficient in sign language, while another is a good speaker or connects with the world through a different sense, such as touch.

One thing that all children have in common (which adults have lost over the years) is their special ability to have a hundred ways of thinking, speaking, playing and dreaming. To maintain this power that children possess is one of our main tasks in teaching, and one of DbI's objectives. Children are our future. Any limitations that we might experience will be overcome by them. We may see them as limitations, they will see as opportunities. It is our task to guide them on this path.

Another matter that I have gained more appreciation about (while in Bucharest) is the collaboration that DbI has

with the World Federation of the Deafblind (WFDB). We look forward to enhancing our collaboration through the existing working agreement (MOU), and making practical working arrangements..

Finally, I should like to say something about Informational Technology (IT) and our DbI work. It's striking how IT is increasingly supporting the quality and intensity of our interactions. This was reflected throughout the many presentations at the Bucharest conference. Having witnessed this gives me, as VP, reason to give this issue more attention. For instance, DbI needs to think more about sharing our member's experiences and successes through live streaming events, remote learning, webinars, etc.

Frank Kat

Opening speech, Gill Morbey

DbI President and CEO Sense International



“Once I knew only darkness and stillness. My life was without past or future. But a little word from the fingers of another fell into my hand that clutched at emptiness and my heart leaped to the rapture of living”.

‘Walking with a friend in the dark is better than walking alone in the light’ – Helen Keller

Welcome to the 16th DbI World conference, hosted by Sense International Romania.

It’s wonderful to be in Bucharest. Cristiana Salomie noted in her early introduction to the conference that Bucharest is known as Little Paris. I know we have all been welcomed and I hope we can repay that hospitality in some small way. No doubt we will enjoy the many places of interest and local attractions.

We will also be publicising the conference widely through DbI Facebook and DbI Review. More of our international colleagues throughout the many countries that we represent will learn that Bucharest has been the Centre of Excellence for Deafblindness this week.

Indeed I have had best wishes from people around the world, including Akhil Paul from Sense International India who couldn’t be with us. Akhil wishes you the best for this conference and reminded me of this Helen Keller quote:

I understand that Romanian legend has it that the city of Bucharest took its name from a shepherd named Bucur. His flute playing reportedly dazzled people and endeared him to the local traders, who then gave his name to Bucharest. I also understand that Bucur translated means ‘joy’. So perhaps our conference should be about joy.

Indeed we have much to celebrate. Tony Best, Chair of the Conference Scientific Committee reminds us of the struggle that we had (and still have) to get deafblindness recognised; but despite the difficulties reaching this objective, we are steadily achieving success. Through efforts that began some decades ago, we are pleased that the disciplines of teaching and supporting children and adults who are deafblind has become professionalised.

Within this over-arching professional umbrella, one of the questions we keep asking is: “are we now grown up sufficiently to let go a bit; to support doing things differently, responding to local

needs and cultures”. We also know that being deafblind shouldn’t and doesn’t define us. A friend and colleague at the Acquired Deafblindness Network (ADBN) Conference last November in Belfast spoke of being an artist, mother, grandmother and then she reminded us: “Oh, I forgot I’m also deafblind”.

We need that supportive base and that over-arching professional umbrella. We have worked long and hard to achieve this recognition and understanding but at the end of the day if we can’t respond and adapt to the needs of the people we support (whatever their circumstances) we haven’t finished our work. So while we must have the high aspiration of professionalism and rigour we must also be flexible and responsive to local circumstances and individual needs. This is a tall order!

As President of DbI, I see countries and programmes all at different levels of understanding and development. Yet we have this bond that brings us together at our conferences and events. The Italian Deafblind organisation’s Lega Del Filo d’Oro, describes this as a golden thread that connects all of us.

And these connections run deep. Sometimes we don’t appreciate that, but if we are lucky we meet people every two years or so then pick up those discussions and friendships immediately. We should appreciate that this is not the same in other professions!

Part of that golden thread is both joyous and deeply sad. We have friends in Nepal where teachers and pupils alike have suffered greatly from the two recent earthquakes; we have children in Bangladesh where unrest has led to huge challenges in keeping their programmes going.

So our deliberations here in Bucharest must be searching and aspirational; but they must be practical as well. What we discuss here must and will make a difference.

I am also CEO of Sense International and have known Cristiana Salomie (Director of Sense International Romania) for many years. Here in Romania, Cristiana and her team have made a difference, starting with early identification, early intervention, through to education. The deafblind

curriculum has been adapted to suit national Romanian standards with huge contributions from the Ministry of Education and support from the Ministry of Public Health; together all having made a difference. SI Romania supports the screening of 80,000 babies, has trained 150 teachers and supports 800 children and families throughout the country

The next steps are just as challenging here in Romania (as elsewhere) as our children move to adulthood, seek vocational training and employment. Seeking support for life is never easy but we must find a way. I'm pleased to tell you that SI Romania has made a great start in this regard by opening 5 vocational centres with two more on the way.

So we look forward to a

conference that keeps our goals high with our feet on the ground. Certainly I can see that the thoughtful presentations will encourage discussion; knowing many of you as delegates, you will not fail to reflect, learn and no doubt challenge.

So finally welcome indeed to our 16th DbI World conference. I know you will have a wonderful time in Joyous Bucharest. Learn, absorb and take the ideas home to your own countries where as the wonderful delegates you are, you will take another step towards making a difference for a child, a family and a deafblind friend.

Gill Morbey
Bucharest Romania,
May 26, 2015

Editor's message *(continued from page 2)*

with deafblindness compensate for the loss of their other sensory functions.

This edition also features 'Self-Regulation of Behaviour in CHARGE Syndrome', another in the series of papers from Dr. Tim Hartshorne and his associates focussing on various difficulties with self-regulation or self-control which individuals with CHARGE Syndrome experience.

Dr. Nadja Hogner presents a very interesting study of stress among individuals in Germany with Usher Syndrome Type 2. Nadja presented her interesting research at the ADBN Conference in Belfast, November 2014.

As usual there are many country reports which present a vast array of exciting activities going on to improve the lives of people with deafblindness. The reports include: summaries of various University research activities (Netherlands), anniversaries (Italy and Argentina),

seminars and conferences (Netherlands and Russia), technology (Australia and Sweden), adventure camping (Australia), deafblind theatre (Russia) and deafblind census (Russia). It was wonderful to receive articles from: Tanne, the Swiss organization, the African Federation of Deafblind and from the new organization in Russia, the Deafblind Support Fund.

While the Networks continue to be active, some continue to struggle with ongoing communication. The Youth Network's 'Got to Act' players were on hand in Bucharest, joined by new members from Romania, to perform the Helen Keller Story. The vibrant Outdoor Network has a call out participation in its annual International Outdoor Week, this September in Norway.

Thanks again to the many contributors for your support. Keep the articles coming!

Stan Munroe

Opening remarks about the program

Tony Best, Chair Scientific Committee

What can you expect from the next few days? What is in the programme, and how can you make best use of the offerings?

Let me say something about how DbI expects this conference, with its theme, to support its work, and then I'll tell you something about the content and what you can hear about in the various sessions.

The countries of Eastern Europe have made spectacular progress in the past few years in developing services for people with deafblindness. At this conference are over 40 colleagues from these countries – representing around 11 % of this international gathering. This wouldn't have been possible just a few years ago, and so being here, in Romania, is a statement from DbI both of our recognition of the achievements, and support of the further development of their services.

The theme

This brings me to the conference theme – Local Solutions to Common Needs.

This conference will take place at a unique time in our history – we are now becoming very clear about the needs created by deafblindness, and know that many of these needs are experienced whenever deafblindness occurs. At

the same time, we have developed as a field, to a stage in which we recognise that there are many different and equally excellent ways of meeting those challenges and supporting people with deafblindness. These local solutions will take account of local culture – the ways families and communities behave and think and live. These local solutions will be excellent in their context, but this is a challenge for each one of us – they may also be relevant to other cultures, or regions. We can each learn and grow professionally by hearing about how colleagues in other countries solve the challenges that are common to all of us.

This stage of maturity, as a field of study, means we are not just consumers or subjects, but men and women with shared interests, common needs, and mutual obligations to each other. The recognition of excellence in different approaches has not always been part of DbI's thinking. Let me tell you something of how DbI has reached this situation.

Probably the first ever conference was in 1962 at Condoval Hall School in England. It was organised by parents – the people who at that time were the leaders – desperate to understand what was happening to their children- investigating, sharing, discussing, campaigning. And the main



speakers at this conference were nearly all medical people. What was Rubella? How did it affect a young child? What could be done to treat it?

By 1971, there had been considerable progress and a conference, held at Perkins School for the Blind in USA, had many teachers in attendance. Experts were telling us how to teach and what to teach; we all collected the wisdom from these pioneers – people like Nan Robbins, Jan van Dijk, Joan Shields, etc.

By 1991, at the 10th International Conference in Orebro, Sweden we started having themes – this one was Quality of Life, and we came together to try to work out the best way to achieve this for deafblind people. And we had started thinking then about adults and not just children.

Of course, most of the work was still in schools and it was only in 1993, at the 3rd European conference

in Potsdam, that the word 'deafblind' was adopted; we began to think of a group of people – children and adults – as the deafblind. Rodney Clark (former CEO of Sense) – here today – was one pioneer who helped create the title Deafblind International and was responsible for many developments at this time. DbI responded further through developing Networks – the special interest groups that brought together colleagues with similar interests and concerns. William Green, Immediate Past President of DbI (also here today) was the person responsible for this success, and many other developments.

In 2003, in Canada, the theme of the 13th Conference was 'communication is the key' and, along with many other topics, there began an effort to better understand communication, and to help achieve it – seeking out the solution, the best way. Stan Munroe, again here today and currently editor of DbI Review, was one of the Canadian pioneers, who led the organisation of that conference, along with others.

In Australia in 2007 the theme of the 14th Conference was isolation focussed on removing the isolation so deafblind people could be part of mainstream rather than being in the backwater.

That conference focussed on how services, training, legislation can be organised to ensure the best services for these isolated individuals.

These themes, and the changes in thinking at DbI conferences, has been reflected in our terminology over the past 40 years: deaf/blind children, the deafblind, deafblind people, people with deafblindness.

So we come to today – but before that I must apologise that in this quick summary, I have not mentioned so many other conferences that were incredibly influential and successful, nor, more importantly, many people who had a significant impact on our field. Never doubt that it is those individuals who have changed the world; in fact it is the only thing that ever has, as Margaret Mead the famous anthropologist so aptly said.

So we come to today, May 26, 2015 when we believe that we understand many of the needs created by deafblindness; but recognise that there is not one solution, but many equally excellent and successful solutions. I believe in the future that this concept may be an important part of our thinking.

The content

What will we learn about at this conference? At this conference 24 % of

the presentations will be primarily about children with deafblindness, while 28 % will include consideration of elderly people and those who acquire deafblindness later in life. For the first time this group of people is a major concern for the field. Adults with congenital deafblindness are the subject of 23 % of the presentations, reflecting the continuing interest in this sector.

There will, as usual, be large number of presentations on 'communication'. These cover a wide range of topics, but two stand out- 'tactile linguality'- the development of language using tactile communication, and 'dynamic assessment' a form of assessment through intervention. Some of you – our leading experts and practitioners – will be talking about these concepts.

Amongst other topics there are several on leisure activities and on mental health (e.g. coping emotionally/ risks/ 'early' intervention on diagnosis) – a new development. There are also talks about digital technology and how it can support people with deafblindness.

Staff development is, as usual, a popular topic but this time there is a changed emphasis on e-learning and on-line training. In part this is making good use of new and emerging technologies, but

“So we come to today, May 26, 2015 when we believe that we understand many of the needs created by deafblindness; but recognise that there is not one solution, but many equally excellent and successful solutions”

“So, that is our conference, a place to seek out the unknown, to risk falling in love, to consider local solutions to our common problems”

also a reaction to the needs of isolated professionals working in non-specialist centres. This is where the majority of children and adults now receive services. I make one observation. In many countries specialist medical services are being concentrated in specialist hospital centres to improve effectiveness and efficiency, but the education and social fields are developing fully inclusive and local services – a formidable challenge for a low incidence and complex disability such as deafblindness.

Two other new trends are apparent. Firstly the development of user-led support, with people with deafblindness integrally involved in the design, development and delivery of services (“nothing for us without us”) for example, in peer mentor schemes, service evaluation by participants, establishing civic rights/entitlements, strategies for taking control.

Secondly, there is an increased emphasis on research-led developments rather than the simple exchange of experiences. For example, studies to evaluate impact of a service, to compare different approaches, to discover what aspects of staff training make a difference, surveys

to establish key needs, and so on. At the same time, the conference will see the launch of a new Network – on Research, with the aim of ensuring future work on evaluation is coordinated and focused in key unknowns.

Lastly, the trend for examining multi-disciplinary working is continuing, with therapists, medical staff, family members all considered part of the team around the person with deafblindness. However, only a few people with these backgrounds are attending as participants. Perhaps this is something for us to think about for the future?

Your approach

So, finally, how do we make best use of these offerings?

Think of entering a forest. I’m just moving from a house by the sea to one in the middle of woodland. And on entering a forest I realise we have altered perceptions; the horizon changes and we may become more aware of smells or touch or temperature. It is a strange place and in northern Europe forests have fascination – magic or scary – this is where folk tales began – the wolf, the witch, the gingerbread house, and the poor woodcutter.

I want to suggest that you think of this idea in relation to this conference. It is a basic

human desire to reach out, to seek the unknown; so be willing to explore, consider the strange, the scary, the magical.

Don’t assume that strangers and strange ideas are hostile. Here at this conference I suggest we should think of being hospitable, of welcoming to new ideas. And this means being open to the curious and the dangerous.

But danger and risk is not, I suggest, a sufficient reason for not being hospitable, and we may even experience the great delight of falling in love – the excitement of what might be – when we meet a new idea.

So, that is our conference, a place to seek out the unknown, to risk falling in love, to consider local solutions to our common problems. It would be good if we could each discover a new idea; it would be great if we could take home something we could develop and put into practice; it would be wonderful if, by accepting something from a stranger, the people we work with receive a better offering that enhances their lives. I sincerely hope you each have a successful conference.

Tony Best
Chair 16th DbI World
Conference Scientific
Committee

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DbI Conference in Romania a Spectacular Success!

On behalf of the DbI Management Committee, congratulations to the members of the local planning committee headed by James Thornberry (Sense International) and Cristiana Salomie (Sense International, (Romania) and the Scientific Committee, chaired by Tony Best (UK) for the exceptional staging of the 16th DbI

World Conference, held in the spectacular of the JW Marriott Grand Hotel, in Bucharest, Romania, May 25-30, 2015.

The conference got off to a welcoming beginning the evening of May 25, with brief words from DbI President Gill Morbey, Scientific Committee Chair Tony Best and Sense International (Romania) hostess Christiana Salomie.

Their brief words were followed by welcome cocktails and finger foods to enrich the evening's collaboration.

Day One (May 26)

The Official Opening ceremony on Tuesday morning, featured welcoming addresses from Gill Morbey (President of DbI and CEO

Opening session
Panel: Gill Morbey, Sunil Sheth, Liliana Preoteasa, and Doru Vlad Popovic



(Below) Cristiana Salomie





Above and left are scenes from Got to Act – DbI Youth Network



Dave Power

of Sense International and Sense UK), Cristiana Salomie (Director, Sense International-Romania), Sunil Sheth (Chairman, Sense International), Liliana Preoteasa (Romanian Minister of Education) and Doru Vlad Popovic (Director of Special Education, Univesity of Bucharest).

This was followed by a theatrical performance from ‘GOT 2 Act’, a group of young performers, based in Cornwall, UK, who are deafblind . They were joined on stage by three young performers with deafblindness who attend a special school for children with hearing impairments in Bucharest. The performance was an account of the early

years of Helen Keller, the famous deafblind activist.

The first plenary of the Opening Day featured an introduction to the conference theme (Local Solutions to Common Needs) from Tony Best. This was followed by an inspirational presentation from Vasile Adamescu, a deafblind educator, author and sculpter who outlined his many achievements along the way overcoming his challenges with deafblindness in Romania.

Day Two (May 27)

The title of the Plenary Session on Day Two was Education and Learning. The session, moderated by Carolyn Monaco (Canadian Deafblind

Association), featured a key note address from Dave Power, CEO and President of Perkins School for the Blind (USA). Dave’s powerful presentation provided commentary on how organizations change over time and how they need to keep re-evaluating their activities to remain viable if they are to properly deliver services in the long term. Plenary respondents included Marianne Riggio (Perkins School for the Blind) who spoke about Perkins International activities; Dmitry Polikanov (Russia) describing



Plenary Panel on Identity and Recognition... left to right: Sonja van den Molengraft, Suzanne Zeedyk, Paul Hart, Chris Woodfill, Isabel Amaral and Akiko Fukuda

the activities of their recently formed organization (Deaf-Blind Support Fund), and Linda Eriksson (Sweden) who outlined the various educational options for individuals with sensory impairment in her country.

Day Three (May 28)

The title of Day Three's Plenary Session was Identity and Belonging, an emotional session exploring the concept

of personal identity and how people with deafblindness develop their self-concept and become part of their community.

This session, moderated by Sonja van de Molengraft (Netherlands), featured the dynamic key note speaker Dr.Suzanne Zeedyk from the University of Aberdeen, Scotland. Suzanne's presentation explored the significance of human being's personal connections

and their importance in human functioning. A few phrases from her message were: Humans are born in relationships; our brains are shaped by human connections; identity is not individual – it is relational; the way we talk to our children becomes their inner voice-their identity, etc.

Plenary respondents to Suzanne's message were Dr.Paul Hart (Sense Scotland), Chris Woodfill (Associate

Education Plenary session: Dave Power, Marianne Riggio, Carolyn Monaco, Dmitri Polikanov and Linda Eriksson



Executive Director from Helen Keller National Centre – USA and North American Representative on the World Federation of the Deafblind), Isabel Amaral (Portugal) and Akiko Fukuda (Japan and Secretary General of WFDB).

Following the morning plenary, DbI made special award presentations for Life Time Achievement, Distinguished Service and Young Professional Achievement; while Perkins presented their prestigious Anne Sullivan awards

The last half of Day 3 was given over to the DbI Networks, the special interest groups that bring colleagues together with similar interests and concerns. The first part of this session featured the nine Network leaders on stage outlining a brief description of their respective networks: Dr. Marleen Janssen & Dr. Paul Hart (Communications), Liz Duncan (Acquired Deafblindness Network or ADBN), Joff McGill (Rubella), Dr. Walter Wittich (Research), Dr. Joe Gibson (Outdoor), Dr. Nadja Hogner (Usher Syndrome), Ricard Lopez

(European Deafblind Network or EDBU) and Dr. Andrea Wanka (CHARGE).

Following this brief introduction, conference delegates participated in their member Networks and/or chose to become new members of Networks.

In the evening following the sessions, conference participants streamed to the Crystal Palace Ballroom for the Gala Dinner which featured an incredible five course dinner, entertainment from students attending Sfanta Maria Special School for Children with Hearing Impairment and Ion Creanga National College, and dancing into the early hours.

Day Four (May 29)

The last day of the conference included a Plenary Session, a Round Table Discussion, several special announcements about upcoming conferences and the Official Closing Ceremony.

- The last plenary of the conference was titled Advocacy and Recognition.

The session featured key note speaker Lars Bosselman (Belgium) describing advocacy and how it can be effective in campaigning for services. Respondents to Lars' presentation were Ricardo Zevallos (Sense International, Peru) and Cristiana Salomie (Sense International, Romania). Ricardo spoke about the effectiveness of their advocacy to put deafblindness into Peruvian law; while Cristiana spoke about their Romanian advocacy successes which included having deafblindness recognized in Romanian law, achieving special consideration for deafblindness education in Romania, among other positive initiatives.

- Dennis Lolli (Perkins School for the Blind – USA) moderated a thought provoking round table discussion titled: What is our future? The round table featured Dmitry Parapanov (Russia), Siriporn Tantaopas (Thailand) and Andrea Hathazi (Romania).

Network leaders on stage outlining a brief description of their respective networks: Dr. Marleen Janssen & Dr. Paul Hart (Communications), Liz Duncan (Acquired Deafblindness Network or ADBN), Joff McGill (Rubella), Dr. Walter Wittich (Research), Dr. Joe Gibson (Outdoor), Dr. Nadja Hogner (Usher Syndrome), Ricard Lopez (European Deafblind Network or EDBU) and Dr. Andrea Wanka (CHARGE)





The round table:
Dennis Lolli,
Dmitry Polikanov,
Siriporn
Tantaopas, and
Andrea Hathazi

- Lars Søybe, from The Danish Centre for Deafblindness and Hearing Loss¹, gave out the latest information about the 9th DbI European Conference that will be held in Aalborg, Denmark, September 5-8, 2017. For more information check out the conference website www.dbi2017denmark.com
- Gill Morbey, President of DbI, announced that the

17th DbI World Conference was awarded to Able Australia² and scheduled to be held on the Gold Coast of Australia in 2019.

- Gill officially closed the conference with a few closing remarks which included the following quotes:
'I don't feel as isolated now'; 'we don't want our past into the future but rather our future into our present'; 'I thought I was an alien but then I realised there were other people on the planet with me'.

registered for the conference, representing 51 countries. The majority of those registered came from Europe and North America, with the largest number (36) coming from the Netherlands. DbI was pleased that 41 people came from Eastern Europe, the largest ever from that region. Other participants travelled from as far afield as Japan and Argentina, with a significant number from Asia, Africa, Australia and South America.

In addition to the plenary sessions mentioned previously in this report, there were 98 workshops presented and 30 poster presentations over the full four days of the conference.

Stan Munroe
DbI Information
Officer (information@deafblindinternational.org)

Handing over
conference from
Romania to
Australia



General conference statistics:

According to conference organizers, just under 400 individuals

¹ www.dbc.rn.dk. The Danish Centre is a small corporate member of DbI.

² www.ableaustralia.org.au. Able Australia is a large corporate member of DbI.

Deafblind International presents awards in Bucharest

Deafblind International (DbI) achieves its goals through its members. Outstanding things happen around the world because of the efforts of individuals who are enthusiastic, motivated and passionate about making life better for individuals who are deafblind.

DbI has the privilege of honoring individuals at events and took the opportunity to present awards to six outstanding professionals at the World Conference in Bucharest in May 2015.

Throughout the world organizations are having a discussion about succession planning; DbI is no exception. Many of the professionals started working with individuals who are deafblind during the Rubella Epidemic years of the 1960's. These

professionals are looking forward to retirement over the next few years. DbI decided that it was important to promote the work of younger professionals and created the DbI Young Professional Leadership Award. This award was presented for the first time in Bucharest to three outstanding women.

DbI Young Professional Leadership Awards

Kitty Bloeming from Visio¹ has a special interest in working with individuals who are congenitally deafblind. She works with the individuals and their families. Kitty is always working to improve the communication skills of persons who are deafblind with additional disabilities. Her colleagues benefit from

her skills in staff development and her research. She was described by her colleagues as an excellent coach who in a quiet and calm way can share her expertise and improve their skills.

Sonja van de Molengraft from Kentalis² is a strong advocate. Her philosophy focuses on including the deafblind person at the table and practices the quote "Nothing about us without us". She is known for her ability to collaborate with others on a national and international level. She was recently selected to be on the EDbN lobby team working with the European Parliament. Sonja works hard and shares her laughter and good humor with everyone she works with.



Kitty Bloeming



Sonja van de Molengraft

¹ www.visio.org. Visio is a small corporate member of DbI.

² www.kentalis.nl. Kentalis is a large corporate member of DbI.



Andrea Wanka

Andrea Wanka³ from Stiftung st. Franziskus⁴ is a motivated ambassador for persons with deafblindness. She is always interested in networking, learning and sharing. She lectures on all aspects of deafblindness and has developed a variety of training materials. Andrea is the chair of the CHARGE Network and serves on the Board of Deafblind International. Colleagues of Andrea say that she inspires them raise the bar in working with individuals who are deafblind. She is an enthusiastic and dedicated professional who works to ensure that children and adults with deafblindness have the best possible opportunities in life.

DbI Distinguished Service Awards

The DbI Distinguished Service Award is presented to an individual who has contributed to the lives of deafblind people.



Richard Lopez

Richard Lopez entered the field to try to find services for his daughter. He not only learned what was important for his daughter but he has advocated for families, children and professionals to create a better world for individuals who are deafblind. His persistence opened doors to greater understanding and his efforts lead to the European Union recognizing deafblindness as a unique disability. His colleagues see him as a man with big ideas and he doesn't give up until he convinces everyone about the importance of his ideas.

Lifetime Achievement Awards

The Lifetime Achievement Award is given to individuals who have spent the greater part of their career in providing services and advocating for services. Two very deserving individuals were presented with the award in Bucharest.



Joseph Morrissey

Joseph Morrissey was honored for his advocacy in promoting services for individuals in Africa. He spent many years advocating for the Rubella vaccination and his work is now one of the goals of the World Health Organization. He helped deafblind individuals form their own federation and encouraged them to speak for themselves. Joe worked for CBM and Perkins International and he was able to open societies that were not tolerant or appreciative of deafblind people. Joe sadly passed away but his work will never be forgotten. His family wrote a letter to accept his award and express their appreciation for the honor bestowed on Joe.



Cristiana Salomie

Cristiana Salomie was busy organizing the conference and just sat to relax at the session when her name was called to receive the Lifetime Achievement Award. She has dedicated her life to improving the lives of individuals who are deafblind. She was able to get the government to officially recognize deafblindness as a unique disability. Cristiana started with two classes and currently there are 15 schools providing high quality educational services for deafblind individuals. Her energy, creativity and leadership skills are endless in making sure that all people receive the services they need.

Bernadette Kappen, Vice President DbI

³ Andrea Wanka is the leader of the DbI CHARGE Network.

⁴ www.Foundation-st-francis.com

Conversation with Vasile Adamescu

Plenary Session: Introduction to the conference theme, DbI World Conference, May 26, 2015

Please tell us a little about your life when you were a child. Were there schools for people with deafblindness?

Almost 70 years ago, I lost my main senses, hearing and sight, due to meningitis. When I was two years old, my family accidentally left me out in a cold autumn rain and I caught a terrible cold. There were rough times, just after the end of the war and my folks gave me the best treatment they could provide for me at home. My grandmother prepared all sorts of teas for me but it was all in vain. In a few months I was left in silence and darkness. My father took me to a doctor when they realized the severity of my condition, but there was nothing left to be done. I remained silent

and unhappy until I turned 11 years old when I was taken to the school for the blind in Cluj Napoca. My condition was new for the school. A committee of teachers and school management were supposed to decide my fate. Many of them were not convinced that there was anything they could do for me. My luck came from Helen Keller, a case well known at the global level. Many teachers had read about her amazing life story and proposed to also try the impossible with me. This is how I ended up a student in the school for the blind. Romania had no specialists in this field, especially because the Romanian school system had never seen a similar case.

So without any specialist teachers, who was it who helped you?

A teacher Florica Sandu came to see me. She was very experienced, having worked in special schools for the blind and deaf. Back then, Florica Sandu was working as a third grade teacher for blind students. She used to take me to her classes where I would sit in the first desk near the teacher's desk. She gave me something to work in parallel with my other older colleagues. After school we would go to the school museum where we spent a long time studying new objects. The teacher's main target was to teach me how to communicate with others. She realized the importance



Vasile Adamescu (left) and interpreter

of pulling me out of the darkness and silence. After months of work she managed to make me utter the first sound, a and p. Then I began to form short words, apa (water), papa (food) and pa (bye). I was very happy. Whenever I met someone, I would tell them these words. It was also a great event for the school: Adamescu said 'a'!

For two years I worked with teacher Florica Sandu in her class for the blind. It was hard for her to work in parallel with me and she didn't have enough time to train me. The idea to make a special class where I would be the single student was proposed to the Education Ministry. After many tries, the ministry agreed and this is how they formed 'Adamescu Class'. It was one of the first steps ever made in the field of deafblindness in Romania. This was happening more than 50 years ago. After 6 years in school, I graduated from elementary school. I was supposed to study 4 years but I had to spend 6 years in order to finish the entire curriculum. I had learned a lot during these 6 years. Teacher Florica Sandu had succeeded to make me speak, to teach me to write and read both in Braille and Latin alphabet, and the most important thing, to communicate with others through Block system. I was very happy with these accomplishments. I remember that back home in Borcea, where I was born, nobody believed that I would ever function as a human being. The only person who believed in my success was grandmother Stanca, my father's mother.

After that successful beginning you had a dream to go to university. Was that possible?

I had a great dream: to go to university. Helen Keller was my motivation. I wanted to be like her. I had learned many trades in school, one of these being typography. Some teachers encouraged me to remain as a worker in the school typography but I didn't want to stay. I tried the entrance examination for Special Education department at the university and I accomplished my dream of becoming a university student. For 4 years I studied a lot, working hard. During my time at the university the Romanian state supported me with a scholarship which I used for my expenses. I started to write my diploma paper in the third year of study: 'Particularities of reality perception lacking hearing and sight'. I graduated from university with very good results and I became a teacher at my former school. I worked in the education system for almost 30 years, teaching children with deafblindness. I have joined the Art School for three years and I perfected my talent in modeling clay. I learned many important things there. I made many clay sculptures throughout the years and I've taught many generations of disabled students the secrets of clay modeling art.

But today have opportunities changed now for young people with deafblindness in Romania?

Throughout the years, many things have changed in Romania in the field of

deafblindness. Back then, when I came to school I was considered blind deaf and mute, now I am considered a deafblind person. The state institutions have understood that deafblind people must receive special treatment compared to those with other disabilities. Of course, there are many other things to be solved. Now there are many special classes where deafblind children learn, protected workshops where they can work, specialists who guide them. Society begins to slowly accept us, to consider us more important than before.

We try, alongside Sense International (Romania) and specialists from our country to make as many good things as possible for this category of people. It is very important to identify deafblind children and to educate them from an early age so as to be able to become useful society members.

What a wonderful story of your achievements as a pioneer, of you, and your inspirational teachers finding your own way to overcome the challenges of deafblindness. Thank you very much for sharing this with us.

Note: Vasile Adamescu recently produced an autobiographical book titled 'Facing Life'. Mr. Adamescu spent 10 years working on this book which was written in Braille alphabet then transcribed by computer and printed for the general public. **Check out more about Mr. Adamescu on YouTube: (www.youtube.com/watch?v=eqnZ6pcipG0)**

More photos from 16th DbI World Conference



More conference photos



Pursuing happiness through Trust, Relationships and Communication¹

Dr. Paul Hart, Sense Scotland

In November 2014, I had the great honour of presenting at the Acquired Deafblind Conference (ADBN) held in Belfast, Northern Ireland. The conference title was Life, Love and Laughter and that was one that excited me greatly, particularly since I was primarily responding to ideas outlined in an earlier presentation from Professor Richard Schoch at the same ADBN conference². He had spoken about the Art of Happiness and Wellbeing and I wanted to build on his ideas and relate them to the importance of trust, relationships and communication in our field. Of course, I was also borrowing some thinking from other writers I have returned to many times for inspiration in other conference presentations and writings over the last 10 years. So this article will summarise that ADBN presentation but also link to some wider thinking around the pursuit of happiness.

The title of my presentation was inspired by the title of Sense Scotland's Strategic Plan³: Transforming lives through trust, relationships and communication which includes the following statement made about the

people who are affected by the plan:

"We value them all and we celebrate their diversity and the different ways they influence the work of Sense Scotland. We want them to be cared for, loved, motivated and trained, to be confident and open and to be inspirational".

Love

I particularly want to stress the word 'love' because I am proud to be associated with an organisation that has the courage to use the word 'love' in its strategic plan because it is love that nourishes us all in the early years and it is love that sustains us throughout our lives. It is love that will transform our lives and we must be serious as a society and as individuals about developing it as early and as earnestly as possible, and sustaining and nurturing it as long as we can.

I try to live a life that includes love, friends and family, but those of you who have heard me speak before, will also know that I have a real affection for mountains, the sea, beer and music. I get access to most of these things on a very regular basis. However, this doesn't

mean I live in a permanently blissed out state of perpetual happiness. But I do know, looking back on my life from this particular point in time, that I am largely happy with who I am as a person. This means accepting the positive and not so positive experiences that have all contributed to making me who I am today. Even the tougher parts of life have contributed to my sense of self.

Relationships and connections

The Scottish philosopher, John Macmurray⁴, says 'the unit of personal existence is not the individual but two persons in a personal relationship'. For me this means that in any analysis of interaction between humans it makes no sense to simply view one side of the exchange without reference to the other.

"It is love that will transform our lives and we must be serious as a society and as individuals about developing it as early and as earnestly as possible"

¹ Plenary Presentation, 10th ADBN Conference, Nov 05-07, 2014

² Professor, School of Creative Arts, Queens University, Belfast (r.schoch@qub.ac.uk)

³ www.sensescotland.org.uk

⁴ Macmurray, J. (1961). Persons in relation. London: Faber and Faber.

Then we have the German philosopher, Martin Buber⁵, who he sets out a brilliant vision where people 'step into relation' with one another, thus contributing to the full revelation of each as a unique person. He describes a particular type of relationship that can exist between people, an 'I-You' relationship, as one of openness, directness, mutuality, and presence.

Whenever I think of relationships and interactions, I turn many times to the wonderful Canadian writer, Judith Snow⁶ (who sadly died at the end of May of this year). She describes this really beautiful image of human life as if it were a thread floating between and connecting bodies, giving each body the capacity to be a person. She suggests if you're alone then of course you are alive but you are not revealed or fulfilled. However, if you come into contact with even one person then new qualities will develop within you. The more you come into relationship with others, then the greater the possibility for you to be fully revealed but also to draw forth new capacity in others.

So I take all of these ideas to mean that it is only by being willing to 'step into relation' with others that aspects of both the real I and the real you can be revealed, and I cannot know who I am except through the direct connections I have with you. So think now of all the relationships in your life, and

how those various people might connect. It is these connections that hold you together, giving you a sense of purpose and identity, in the way that Judith Snow describes.

This makes me think about the people I am in a professional relationship with, and here I am principally thinking of people with congenital deafblindness. What kind of roles and identities do they get to play? If they are uncles do they get to do 'uncle-type' things? If they are sisters do they get to act just as sisters, or if they are sons do they get to be sons? Then we could ask are there sufficient opportunities for people to play some of the other roles that might be possible in life? Could they be friends, lovers, artists, or sportswomen? And then what of people who become deafblind later in life? What if someone's vision or hearing changes much later in life? If they are wives or husbands just now do they get still to be wives and husbands, and how does deafblindness impact on their identity, as well as connections with other people in their life? If they have partners, do those partners still get to be wives or husbands?

Happiness

If I really believe what these various writers tell me, then any major change in our lives will bring both exciting challenges as well as difficult challenges. New situations and new contexts will mean

that we can find out new aspects of ourselves, more profound insights into our own personalities and who we really are. In turn, this will also mean other people in our lives will find new aspects of themselves also. This could be exciting as we strive for happiness, but these new situations and new contexts also mean that the important relationships in our lives will have changed. Important activities that provided value and purpose may also have changed, and indeed, our very sense of identity may have changed. These will all impact on our pursuit of happiness and our sense of well-being.

Richard Schoch reminded the ADBN conference that happiness lies within us. We should strive to become not someone else but a better version of the person we already are. But additionally, if we blend some of those ideas already discussed around connections and relationships with Richard's idea that the activity of becoming happy is one that binds us to the world, then the place to look for happiness, indeed the place to cultivate happiness is at the meeting place between people. Happiness is to be found in the relationships and the connections that we have with people in our lives.

A personal story of connection

I will give a personal story to illustrate this idea of threads connecting us. Somewhere around ten years ago, I became ill. After visiting my

⁵ Buber, M. (1996). *I and Thou*. New York: Touchstone.

⁶ Snow, J. (2000). *The Power in Vulnerability*. In J. O'Brien & C.L. O'Brien (Eds). *A Little Book About Person Centred Planning*. Toronto: Inclusion Press.

Doctor in the morning, I went to see my boss, to say that I might need to be off work for a few weeks, or as it turned out a few months. But what really struck me was what happened that afternoon and evening. I had told one friend that I was unwell, who in turn told another, who in turn told another and on it went. My brother was at my front door within a few hours, many friends sent messages of support, offered to do whatever was needed, one offered to put me up as and when required so I could focus on recovering, people planned visits to me over the next few days and weeks. As all these threads, these connections to people in my life tightened and pulled together, they added enormous strength to every other thread and I felt truly held in a safe space. No matter what happened with doctors, hospitals or health professionals, I knew I could not fall too far, because there were so many threads supporting me, each individual thread providing the others with strength. It was a remarkable feeling.

I want to highlight one particular visit to a friend I'd known for many years. When he had been a teenager some years before, I had very often been in a caring and supportive role to him. Whenever he was having a hard time, or needed support to make a big decision in his life, we would often go to a lake not far from where he

stayed and we would just skim stones along the water as he thought about his life. Soon after my visit to the doctor's, I went to see him. I walked into his house and he saw right away that I wasn't looking my best. He said, keep your coat on we'll head out in the car. He drove straight to that lake, and we stood on the lakeside skimming stones. After maybe 15 minutes, he just turned and said: 'So what's up, anything I can do?' And in that moment, our roles reversed. Up until that point, it was me who had most often been in the caring, supportive role, but my illness allowed him the opportunity to adopt that role for himself. It was a reminder to me of the power of vulnerability and its ability to reveal aspects of another person. In recent years, I have been reading the wise words of Brene Brown⁷ who writes about vulnerability. It strikes me when I read her books, that any of us can allow other people to find new capacities in themselves, but we first have to lessen our need to have all the answers. Looking around many disparate fields, this appears to be true of a good teacher who sees his pupils as equal in the learning process, effective communication partners who step out on a journey of co-creating language in the tactile modality, inspirational managers who loosen their grip on authority and power, in order to allow colleagues to take on creative leadership roles.

Social Interactions

I have written elsewhere⁸ about the work of Andy Meltzoff⁹ who suggests that when babies are interacting with others through imitation, they are learning that the other person is not an alien but a kindred spirit. Not an it, but an embryonic you, and this is one of the most important outcomes of imitation; it allows the infant to see the adult as just like me. But we can see that same thing happening in interactions involving adults who have perhaps lived for many years with limited social interaction. If someone gives you an imitative response, in that moment you will experience yourself as an I, and that must be profoundly life changing. But the real magic of imitation, and indeed any effective interactions between two people, happens when the other person is revealed as a you, for the communication partner, and maybe endowing that person with humanity that up until then had not been visible. This is a fellow human being, someone equal to you. So imitation serves the same purpose for a communication partner as it serves for an infant in those early moments of life, it shows the other person to be just like me. It reveals the other person. And it opens up the possibility of trusting in another person.

The 19th Century and early 20th Century American psychologist, William James¹⁰

⁷ www.brenebrown.com

⁸ Hart, P. (2006). Using Imitation with Congenitally Deafblind Adults: Establishing Meaningful Communication Partnerships. *Infant and Child Development*, 15(3), 263-274.

⁹ Meltzoff, A. N. (2002). Elements of a developmental theory of imitation. In A. N. Meltzoff, & W. Prinz (Eds). *The imitative mind: Development, evolution, and brain bases*. Cambridge: Cambridge University Press.

¹⁰ Cited in Reddy, V. (2008). *How Infants Know Minds*. Cambridge: Harvard University Press.

developed an idea that the worst fate to befall a human being would be to wander around in the world completely unnoticed, never a single person ever paying you any attention. In Judith Snow's terms, such a person would be alive but certainly not revealed. The desire to be in touch, to connect with other people is profoundly strong, but it takes a partner who is willing to see this other older person in front of them as a 'you', and not an 'it'. I believe we never lose this desire to be the 'you' of someone else's attention.

For me this is not just an academic question, because in our societies there could be many people who are waiting to become the 'you' of someone else's attention. For example, this could be an elderly person living at home alone where hardly anyone comes to visit, or in a nursing home where people do not know how to make contact with you. Alive, but not revealed – where has any consideration of their happiness gone?

Challenges

Of course, there are challenges in maintaining connections for people who might need support to make this happen? Could you be supported to maintain, let alone develop, friendships and social connections? Could you be supported to shop only for pleasure, to eat out with friends, to hang around on a street corner, or just pop round to a friend's house?

It might be possible to get support to do your weekly grocery shopping, or to go for a trip to the bank, but would it be so easy to convince a funding authority to provide a communicator guide so you can pop round to visit your friends, or have a fun-filled night out in the pub, or to host an evening party in your own home? But we know that this makes life worth living – it is these connections that guide our pursuit of happiness.

Conclusion

I will conclude by returning to a quote from Albert Schweitzer¹¹: *“success is not the key to happiness; happiness is the key to success”*. And for me at least, if you love, what you are doing you will be successful. And so we could ask ourselves, do we love what we're doing? Or maybe we could go further and reject the idea of doing and in its place think of being. This would allow us to put the question another way. If you love who you are, you will be successful. The only thing any of us really has to do in our lives is simply be true to yourself. Be a human being and interact with other human beings. (Or indeed, another human being?) How we choose to be, however, that is up to us and, for me, it is the key to our happiness and our success.

To know that life is about being yourself, but also knowing also that you are part of something bigger, and this helps us to return full

circle to the ideas from Judith Snow and Martin Buber. Albert Schweitzer put it much more poetically: “just as the wave cannot exist for itself but is ever part of the heaving surface of the ocean, so must I never live my life for itself, but always in the experience which is going on around me”. For me this is what really helps me in my pursuit of happiness – a willingness to accept who I am, and then step into relation with others in a way that really accepts them for the individual they are, allowing the full revelation of their unique creative gifts, allowing them just to be.

I will finish with words I have used before, at the 14th DbI World Conference in Perth Australia in 2007. We can choose to see the tragedy of difference, whether this be disability, sexuality, religion, ethnicity, because in seeing difference we might imagine those people to have lesser stories, not belonging to my group, not connected to me. Or instead we can choose to see the miracle of difference because difference gives us the opportunity to listen to new stories, to belong to more groups, to make more connections, and doing so we become richer human beings. Our full capacities as individual inhabitants of this planet get fully revealed, and in this process we can further strive for happiness.

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¹¹ Albert Schweitzer, *Civilization and Ethics*, chapter 26.—The Philosophy of Civilization, trans. C. T. Campion, part 2, p. 321 (1949, reissued 1981).

Guided by Scent¹

A discussion about how scent can be used in the support of people with deafblindness

by Marian Waanders–Westman

Introduction

What if you can hear but not see? – Pictures are meaningless to you? What if you can see but cannot hear? – Conversations or music are not perceived. However if both words and pictures are meaningless to you, there is still much of daily life that you can experience. Even with loss of the senses of sound and sight, a most underestimated sense is likely still there: smell.

During my work in the past 30 years, I have seen many new products and methods made available to compensate disabled people for their sensory loss. The focus of these enhancements has been on loss of sight and sound; very few have been on smell.

For some years I wished to write an article suggesting means of supporting such disabled people as those with deafblindness, dementia or with severe mental disabilities through the use of scent. Many of these individuals cannot hear or understand our words anymore; they cannot see or recognize their surroundings.

I am convinced that the quality of life for these individuals with vision and hearing loss will be improved through a deliberate and consistent use of scent in their professional support. This year I had my book 'Guided by

Scent' published about this topic.

Smell – a special sense

The act of smell is two-fold – taking in air for respiration and influencing taste for the food we eat. Ninety percent of our taste is influenced by the scent or smell of it.

Scents have a great impact on our daily behaviour in an unconscious way which represents the great power of scent.

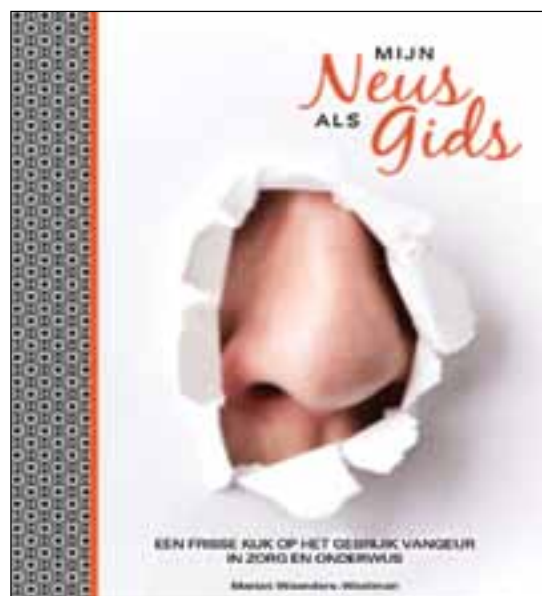
Example:

During an experiment, subjects were offered a crumbly cookie, which they had to eat. In the first round, a slight scent of a detergent was around in the test room. In the second round they removed the source of the scent. Observation showed clearly that when the scent of a detergent was present the subjects were more likely to sweep the crumbs and keep the table clean.

Scent and memory have a strong relationship. Many memories have an association with a particular event invoked by a scent. A smell can act as a flashback or trigger to remembering an event or experience.

Example:

The scent of freshly mown grass may bring one back to



a bewitching summer holiday in France. You instantly know when, where and how you may have met a special friend, etc.

There are some arguments that this connection might be partly explained through an association of the olfactory system to the limbic system, a part of our brain where also our memory and emotions resides.

Scent and emotion also have a strong positive relationship. A special scent

¹ "Guided by Scent" is the English name for the Dutch book "Mijn neus als gids", Published March 2015.

can bring one to a pleasurable mood while taking a stroll in a forest during spring.

A scent can have the opposite effect as well. Experiencing a trip in the crowded metro with many noisy individuals can be very irritating.

We treasure all our own unique memories and experiences through scent.

Support by scent

There are a number of different ways that persons with deafblindness living in supported facilities can be assisted in their daily lives through the positive use of scents.

- Increasing the feeling of safety
- When we seeing and hearing people move to a new house, we generally clean the house thoroughly, buy some new furniture, do a fresh coat of paint and last but not least purchase new bed linen. Primarily these improvements are all about the visual aspect. For a person with deafblindness, all those new scents would lead to much confusion despite their noble intentions. A better idea for these individuals changing their home would be for them to use their 'old' unwashed bed linen. The memory of their personal odour will provide a feeling of safety in an unfamiliar

environment overloaded with new scents.

Improving alertness

- Experience reported from some residential facilities for people with deafblindness, suggests that the alertness of these individuals can be improved following the lunchtime period through the use of an aroma diffuser to disperse an essential oil with a citrus scent.

Recognizing a special person

- On 'YouTube' there was a recent post of a father carrying a baby. The father used to wear a beard and moustache. After shaving, the baby at first did not recognize his father. In the segment, one saw the hand of the baby touching the chin of his father without a sign of recognition. A few moments later, when the faces of the father and the baby were very close to each other, the baby eventually smiled after smelling a familiar odour.
- Similarly when working with people who are deafblind, wearing the same fragrance, necklace or bracelet will make it easier to be recognized. The senses of touch and smell will eventually strengthen each other.

Recognizing a special room

- A deafblind girl with a mental disability had difficulty falling asleep; in fact she only wanted to sleep in the living room. She regularly awoke during the night wherever she slept in a very fearful state.



Her parents and professionals wishing that she sleep in her bedroom rather than the living room, considered using scent as a stimulus to strengthen the function of the bedroom for sleeping. Aroma diffusers with a relaxing lavender scent were placed in the various places she ought to be sleeping: her own bedroom, her bedroom at her grandparent's house and the bedbox at the childcare. Consequently all places had the same lavender odour and, from that moment on, no further activities like changing diapers were carried out in these bedrooms anymore. In this way the connection between the lavender scent and the bed became more powerful.

² <https://www.tsbvi.edu/seehear/summer05/smell.htm>

As a result this girl falls asleep in her own bed and does not wake up during the night as regularly as before.

Recognizing a special activity

For example, if someone with deafblindness goes out for a regular activity such as horse riding, try to arrange for the person to have their own personal riding cap. Encourage them to feel and smell their cap when they are about to leave. Support this with the sign for horse riding. On the way to the riding school the child should keep their cap with them to smell to help awareness of where they are going. In this way scent can be used as a reference and a reminder.

If a child is going swimming, let them feel and smell their own swimming clothes. If your child is having a bath, let them smell their favourite bath oil to prepare for what is coming.

Just for joy!

One mother of a daughter who is deafblind provided an



example of her use of smell to help her daughter with her love of making paintings. When she paints roses, the mom pours some rose extract into the paint, making for her daughter even a more joyful experience.

Summary

This article presents just a few examples of the creative use of smell that can be used to support individuals who are deafblind. More detailed background and practical information about this topic is contained within the book "Guided by Scent".

Readers will be provided practical suggestions where scent can be used in the daily life of the individuals they may support. The book features humorous cartoons

about smell including a smell through the use of smelling ink on one special page.

This colourful and easy to read book is targeted for professionals working in the field of Education and Care for individuals with severe mental disabilities, dementia or deafblindness; fields where scent is rarely used in support for these individuals.

Currently the book is only available in the Dutch language with an English translation planned for the future.

About the author

Marian Waanders-Westman is a Speech Therapist and owner of Clarent, a privately owned company which coaches and trains professionals working with disabled people. She has 30 years consulting in the Care and Education field.

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Editors note: To find out more about the significance of scent to deafblind services (which Marian Waanders-Westman suggests in her article), check out the paper referred to in footnote #2. In Gloria Rodrigues-Gil's article (The Sense of Smell-A Powerful Sense, she describes in more detail the connection of the olfactory system with the limbic system. She also brings attention to the fact that deafblind children have a sensitive sense of smell which she believes compensate for their other sensory losses. Her paper supports the Marian Waanders-Westman position that deafblind people's strong sense of smell can be used positively to support these disabled individuals.

Africa

The African Federation of the Deafblind



Bring you warm greetings from the African Federation of the Deafblind (AFDB) and the people of Africa. This report highlights the regional work dating from October, 2009. It specifically relays the successes, lessons, challenges, and the possible way forward for greater emancipation of deafblind persons on the African continent. In the same breath, the report provides a brief reminiscence of who we are under our regional umbrella, our vision, mission and values.

More about us

The African Federation of the Deafblind represents one of the six constituents of the World Federation of the Deafblind (WFDB)¹. It is a continental body established in Kampala Uganda, on October, 2009 under the auspices of the

WFDB and Myright² (formerly called SHIA). It comprises 13 member countries namely: Burkina Faso, Congo -Brazzaville, Ethiopia, Ghana, Ivory Coast, Kenya, Tanzania, Uganda, Malawi, Mali, Nigeria, South Africa and Zambia.

Our Mission

To empower the National Deafblind Associations to be the unifying voice of deafblind persons in Africa ensuring deafblind people are recognized as persons with dignity, equal rights and opportunities.

Our Vision

To advocate for a barrier free society that will allow persons with deafblindness to actively participate in the activities of their national activities.

Organizational Structure

AFDB is constituted primarily by national member organizations of deafblind in Africa. The membership is currently organized into five regions namely, Central Africa, East Africa, North Africa, Southern Africa and West Africa. Other members of AFDB include International and honorably members.

A General Assembly consists of delegates from the member national organizations. The members, outgoing Board, International and honorable member meets every five years to review the policies and progress of the Federation. The General Assembly elects and confirms the President, Vice President, Secretary General, Treasurer and 5 regional representatives for a term of five years. The board of officers meets at least once every year to transact business on behalf of the general assembly.

More photos from 16th DbI World Conference



Africa
continued**Update of Activities**

Since its founding General Assembly, AFDB has had the following activities:

- Two board trainings in South Africa and Uganda in 2011, facilitated by the Institutional Development Program, during which time the Strategic Plan was developed.
- Organized a partners meeting in Ghana during the 2011 African Forum.
- Participated in the General Assembly of the Secretariat of African Decade of Persons with Disabilities in 2010.
- Registered the following new member countries: Cameroon, Eritrea, Namibia, Mozambique, Somalia, DRC and Zimbabwe.

- Formulated a draft Systems and Policies document.
- Participated in the WFDB General Assembly – Helen Keller World Conference, Tagatai, Philippines, 2013.
- Participated in the post 2015 millennium Development agenda, in Nairobi Kenya early this year.
- The President participated in the following WFDB meetings: Hua Kin, Thailand (2010); Sao Paulo Brazil (2011); Executive meeting in Thailand (2014)

Experiences

AFDB believes that frequent interaction with other members helps to share ideas, challenges and solutions. The interaction could be in the

form of e-mails, meetings and workshops.

Challenges

- AFDB does not have a secretariat to act as a central point for operations and policy implementation. Work is underway that this secretariat will be eventually established in Malawi.
- Communication difficulties among Board of Officers due to language barriers.

Prepared by: Ezekiel Kumwenda, President AFDB
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¹ www.wfdb.eu. WFDB is a partner organization with DbI.

² <http://iddcconsortium.net>

**INSTITUCIÓN SULLAI**

Instituto Especial para multimpedidos sensoriales y con alteraciones en la comunicación – Asociación Civil sin Fines de Lucro
 Gaspar de Medina 333 B°
 Marques de Sobremonte,
 Cordoba, Argentina
www.institucionesullai.com

Stories in Colors

Artistic expression, while considered a significant activity enhancing an individual's personal development, is also recognized as an important part of education. Art provides an opportunity for all of us to explore and demonstrate our individual talents. Opportunities showing personal creativity are probably those which generate the most enthusiasm among participants.

During the celebration of the 20th anniversary of the

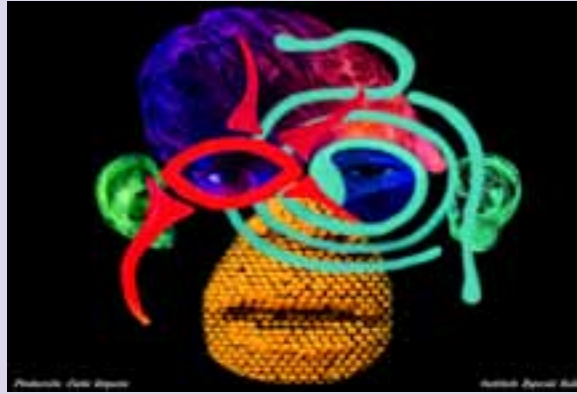
founding of Institution Sullai held at the end of the school year 2014, an auction of works of art was organized to show the work of our students with multiple disabilities.

The idea originated from the success of the experience of our students experimenting with a technique involving different components, fluorescent materials together with black light. Their experiences using various materials, textures, and colours created an experiential awakening among the students which fostered the desire for further

Argentina

Karina Medina

Argentina continued



creativity. From a small beginning, this activity was expanded throughout our entire institution.

This experience created not only fun for the children and young people, but also for the teachers. It revealed that the students with cortical visual impairment could become active creative participants when a stimulus was presented which had real relevance to them.

The success of this activity gave us the idea that we should share these experiences with the community to show some of our successes over the past 20 years. What we did was to create a gallery of photographic images to permanently document the student's different stories, ideas, emotions, feelings and values.

The photographic gallery of 16 individual

productions demonstrated a variety of techniques including those using the fluorescent materials with black light, together with other techniques selected by each teacher and designed specifically for a particular group of students.

During that celebratory event, guests were invited to the gallery to enjoy the productions, and if interested, purchase the items through a silent auction.

The silent auction was a great success as each unique piece was acquired by either a family member or someone from the community. More importantly, the expression of interest by the public in this event reinforced the idea to staff members that the artistic talent possessed by these disabled individuals should be shared with the public on a regular basis.

We are grateful to the

educational community of Sullai Special Institution and to photographer Carla Urquiza who donated her professional fees to make the productions.

Copies of the original photographs (in postcard format) were available for sale at the DbI World conference in Bucharest, Romania, May 25-30, 2015.

Karina Elizabeth Medina
Principal, Sullai Institute
Email: kari28974@yahoo.com.ar

Note: SULLAI Institution provides services to children and youth with additional visual disabilities including those with deafblindness. It was founded in 1994 by two mothers and three professionals in the absence of programs for the care of their children with multiple disabilities.



What is the Australian DeafBlind Council?

By David Murray, ADBC Administrator

The Australian DeafBlind Council (ADBC) has returned to the advocacy podium with a new Administration Officer.

My name is David Murray and I have been appointed as the sole administrator to support ADBC's Executive Committee, provide information on deafblindness, facilitate deafblind advocacy forums, and build professional relationships with deafblind organisations, their supporters, families and friends.

ADBC is a National Advocacy organisation guided and managed by the Executive Committee. The committee board consists of Michelle Stevens as President and Stephen Hardy as Vice President. Both they and another committee member, Heather Lawson, are deafblind.

The Committee also includes representatives from two professional organisations that specialise in supporting people with deafblindness – Carla Anderson from Able Australia and Matthew Wittorff from Senses Australia. We are currently recruiting for the final committee positions,

including a 'deafblind family member'.

Not only am I ADBC's Administrator, I am also deafblind with Usher Syndrome 2 – one of the most common forms of deafblindness. My personal experience is from the field of health and humanities. I understand the importance of having an organisation like the Australian DeafBlind Council to represent the Australian deafblind community.

The ADBC is a place for deafblind people to turn to when they are seeking security, support and information. We understand the challenges of being deafblind and can support people with deafblindness to seek empowerment and learn new skills in self-determination and self-organisation. ADBC represents deafblind individuals, groups and their communities to ensure full participation without inequity and resistance.

For the past seven months, I have been working to modernise the ADBC's new constitution which defines the peak advocacy roles in increasing community access

for deafblind people. Recently, I travelled to the other regions of Australia to meet with other state-based deafblind groups. I have provided moral and peer support and offered strategies to improve or cope with the barriers they face being deafblind.

This year, the ADBC also had the opportunity to communicate the challenges faced by deafblind individuals and the services they require to the Federal Government. This was part of a submission report to support the Government's new funding delivery program called the National Insurance Disability Scheme. The ADBC hopes the Australian Government will understand the nature of deafblindness and the need for specialised support, as well as provide accessible opportunities that meet the needs of deafblind individuals.

Australia is the sixth largest country in the world and the ADBC has a challenge to identify every deafblind person. As a result, we are currently supporting the expansion of deafblind support services to deafblind people living in remote and regional areas of Australia.

I am passionate about my

“We understand the challenges of being deafblind and can support people with deafblindness to seek empowerment and learn new skills in self-determination with self-organisation”

Australia continued

role and continue to work hard to increase the level of support available to deafblind people. I continue to advocate the need to increase funding and communication support, as well as providing an empowering voice to provide deafblind people with greater access to their community.

Other projects include:

- Modernising ADBC's new constitution
- Increasing ADBC membership
- Establishing state-based self-advocacy groups

- Generating funding opportunities for deafblind people
- Increasing deafblind awareness to the Government and other organisations.

I hope to call upon and extend my connections within the international deafblind community and their supporters to share the knowledge, skills and experiences that may benefit the life of deafblind people around the world.

The Australian DeafBlind Council and deafblind community would like to thank Able Australia and Senses Australia for their financial support to continue as a peak advocacy organisation.

For further information on the Australian Deafblind Council and memberships:

David Murray,
Administration Officer
Australian Deafblind Council
info@deafblind.org.au/www.deafblind.org.au

¹ www.deafblind.org.au. (The Australian Deafblind Council is a small corporate member of DbI)

Western Australian “Wild Western Deafblind Camp”

Senses Australia was very proud to host the “Wild Western Deafblind Camp”, November 14-16, 2014 at the Ern Halliday Recreation Camp¹, Hillarys, Western Australia. The WA Deafblind Camp provided an opportunity for people who are deafblind to come together, catch up with friends old and new, share experiences and engage in recreational activities and outings in an environment that was safe and supportive. Fifty Deafblind people from all over Australia and two people from New Zealand attended the camp this year. This was the largest gathering of Deafblind people in Australia, ever. To ensure campers had the best experience, volunteers



who numbered over 100 were there to provide one to one communication and sighted guide support. Volunteers were trained in the areas of: What is Deafblindness, causes, impact, communication, making contact, do's and don'ts and sighted guide training. Along with tactile and hand over hand training, many of the



volunteers put in fifteen hour days and were tireless in their commitment and support of our campers. A huge thank you to all the dedicated volunteers (new and old) who embraced the Deafblind community; we couldn't have done it without you. Feedback from deafblind campers on the volunteers included:

- “All the volunteers were fantastic”
- “I did have a good time. I got lots of help with communication, I was lucky.”
- “Very relaxed and the volunteers worked hard to ensure everyone could participate.”

On arrival on Friday afternoon campers were given time to settle in and orient themselves to the campsite.

¹ www.dsr.wa.gov.au/camps/locations/ern-halliday member of DbI)



Australia continued

A meet and greet was held in the dining hall, followed by the evening meal and lots of catching up with friends old and new. In the evening the “The Pioneers” bush band set up and gave campers an introduction to the steps required to participate in the big barn dance on Saturday night.

On Saturday morning campers participated in a variety of recreational activities, including: abseiling², flying fox³, archery, caving, indoor rock climbing and crafts. On Saturday afternoon we travelled off site along the coast road to Kings Park in central Perth, where campers and their volunteers enjoyed beautiful views of Perth city, visited war memorials, walked along the tree top bridge and enjoyed the beautiful gardens. We then departed Kings Park for Conti’s Winery’s, where campers greatly enjoyed tasting the local wines, cheese and biscuits.

On Saturday evening the first ever Deafblind barn dance was staged. Campers and volunteers were full of enthusiasm and fancy footwork and we all danced well into the night. Everyone embraced the Wild Western theme with some fantastic costumes and lots of happy snaps taken in the photo booth to remember the night. Campers were asked to feedback on what they liked the most about camp, comments included:

- “Socialising and meeting new people and old friends”
- “Good to see so many people laughing having fun and dancing”
- “Everything mostly dressing up and the dance”
- “Bushdance was brilliant”

Awards were delivered for best costumes and best dancers. Many thanks to our stoic judges: Debbie Karasinski (CEO Senses Australia), Elvira

Edwards (General Manager, Client Services) and Matthew Wittorff (Manager, Deafblind Services).

On Sunday morning campers were on the move again and given a variety of activities to choose from. Many went to explore the Hillarys Boat Harbour while

“Campers and volunteers were full of enthusiasm and fancy footwork and we all danced well into the night”

others enjoyed tandem bike riding, swimming and canoeing.

We then all reunited for a panel on the National Disability Insurance Scheme⁴. Many thanks to our informative panellists: Carla Anderson, Justine Lorenz,



² Abseiling involves descending rope(s) using a friction device (e.g. belay device) attached to a harness

³ The term “flying fox” is most commonly used in reference to a small-scale zip line

⁴ www.ndis.gov.au

Australia continued

Matthew Wittorff and Rita Kleinfeld-Fowell. There were lots of questions and great discussions around this exciting initiative. We then all enjoyed a goodbye lunch and the speeches began. Many campers got up and expressed their happiness at having been able to participate in this fantastic experience. A few comments from campers are listed below:

- *The best camp I've ever attended*
- *Well organised, the communication support and volunteers enabled me to*

communicate with others, meet new friends and new challenges

- *Experienced lots of new things and was smiles all weekend*
- *Senses did a fantastic job*
- *I loved every minute of it*
- *Loved socialising and meeting new people and old friends*

This camp was generously supported by Perpetual Trustees⁵, NDS Community Living and Participation Grants⁶, Charity Direct⁷ and Senses Australia⁸. Again a

huge thankyou to everyone who participated and contributed to the success of this camp and we hope to see you all again in two years. If you would like to see more of the photographs and comments from camp please visit us at the Deafblind Information Website (www.deafblindinformation.org.au), 'Usher Syndrome Support Group (WA)⁹' and Senses Australia.

Karen Wickham
Camp Coordinator /
Senses Australia

⁵ www.perpetual.com/

⁶ www.clpg.org.au

⁷ wacharitydirect.com.au

⁸ www.senses.org.au. (Senses Australia is a small corporate member of DbI.)

⁹ www.geneticandrarediseaseneetwork.org.au/support-groups/view/99

Let's Connect: Outcomes and future directions

By Meredith Prain PhD, CPSP

Speech Pathologist, Let's Connect Project Officer, VIG practitioner



The original Let's Connect project was funded by V. V. Marshman Trustees and coordinated by Able Australia¹ to provide: a) deafblind awareness training to other service providers and b) assertiveness training to people with deafblindness and their families and carers around Australia. After three years, this project was reviewed and approved for funding for a second phase. This second phase consists of two parts as well – meetings twice a year with representatives from around Australia and deafblind awareness training.



Deafblind Awareness Training

The deafblind awareness training was divided into two half day sessions – one working with people with congenital deafblindness through the work done by

the DbI Communication Network and the second working with people with acquired deafblindness. Attendees came from various professional backgrounds and services including allied health therapists, social workers, disability support workers,

¹ www.ableaustralia.org.au. Able Australia is a large corporate member of DbI.

early intervention teachers, disability employment consultants, orientation and mobility instructors, case managers and teachers.

Assertiveness Training for People with Deafblindness

Guest speakers from state-based Equal Opportunity and Anti-Discrimination Commissions were invited to attend this program to discuss legal rights and processes for making complaints. They were joined by representatives from the advocacy organisation Blind Citizen's Australia². Funding covered the cost of interpreters and note takers for people with deafblindness. Costs for this services were reduced by through the support of various organisations around Australia, including Able Australia. Other supporters included: The Forsight Foundation³, Senses Australia⁴, Deaf Services Queensland⁵, Guide Dogs Tasmania⁶ and Kilparrin School⁷ who provided training rooms at no charge and support staff.

National Let's Connect Meetings

At the end of the first phase of the project, two representatives with deafblindness from each state in Australia met to discuss what was most needed. All agreed it was valuable to meet face to face



and so regular 'in person' meetings were incorporated into the second phase of the project. One meeting each year was held before the National Deafblind Camp⁸ which provided an opportunity for people who had never attended the camp before to meet more people with deafblindness from around Australia.

The National Let's Connect meetings take three hours and typically include a guest speaker and updates from each representative. This provides an opportunity for people to learn about the various activities in each state and promote what's happening in their own states.

In the second phase of the project, a Deafblind Action Information Officer was employed to share information about advocacy opportunities and keep a record of the advocacy

activities of the Let's Connect representatives.

Key outcomes and learnings from the project

Everyone who participated in the Let's Connect project has reported it has been a valuable experience to have been involved in. Three of the Let's Connect representatives gained employment during the project – two specifically in the area of deafblindness and one in the disability sector. Many have moved into roles on the Australian Deafblind Council⁹, while one representative set up their own state-based advocacy group.

The opportunity for people with deafblindness to come together to discuss the issues which impact on their lives is valuable in fostering a sense of connection

² www.bca.org.au

³ www.forsightfoundation.org.au. The Forsight Foundation is a small corporate member of DbI.

⁴ www.senses.org.au. Senses Australia is a small corporate member of DbI.

⁵ www.deafservicesqld.org.au

⁶ guidedogstas.com.au

⁷ www.kilparrin.sa.edu.au

⁸ See article about the recent National Deafblind Camp in this edition

⁹ www.deafblind.org.au. The Australian Deafblind Council is a small corporate member of DbI.

Australia continued

and community, reducing isolation and developing new knowledge and skills.

Future directions

Able Australia is delighted that V.V. Marshman has recently agreed to fund the Let's Connect project for a further three years with a view to making the project more sustainable. As the National Disability Insurance Scheme¹⁰ is introduced in Australia, it is anticipated that more funding will be available to people with deafblindness in Australia so they can pay for the interpreter and communication guide support required to attend the Let's Connect meetings.

Let's Connect representatives will also be more involved in learning how to run the Deafblind Awareness training over the next three years.

If you have any questions about the Let's Connect project, please contact Meredith Prain , Let's Connect Project Officer, meredith.prain@ableaustralia.org.au

Checklist when planning training for people who are deafblind

Key things to consider:

- People with deafblindness tire more quickly due to the concentration required to take in information so sessions ideally should not go longer than three hours
- Workshops should be held at a venue close to public transport



- Workshops should be held at a time that participants can avoid peak hour congestion on public transport
- Prior to the workshop check with participants if they require:
 - Visual frame interpreter
 - Tactile interpreter
 - Close range interpreter
 - Note taker
 - Audio loop
 - Braille or large print agenda
- Book interpreters giving booking agency as much detail as possible about individual participant needs
- Ensure there are enough interpreter tables for all participants requiring tactile and close range interpreters
- Ensure the training room has an audio loop if required
- Produce agendas in alternative formats as required
- Ensure training room has good lighting
- Ensure one wall has a dark constant background. Use large black screen or cloth

if necessary for interpreter and speaker to stand in front of

- Ensure there is adequate support for participants during breaks.

During workshop

- Do not use power point presentations as most participants will either not be able to see if, or not be able to take in the information as they will be focused on their communication support
- Use clear simple language
- Break for 1 – 2 minutes to change interpreters every 15 minutes
- Break every 30 minutes to allow interpreters and participants to rest for 5 minutes
- Ask participants to stay seated during short breaks and only to get up at refreshment breaks or the breaks will extend too long and reduce the time the speakers can talk
- Pause from time to time to ask if there are questions or comments.

¹⁰ www.ndis.gov.au

iLearn Share – a peer training model

By Claire Tellefson, Ablelink/Digital Literacy Coordinator

Able Australia is supporting people with deafblindness to remain socially connected through a range of innovative adaptive technology programs.

The Not-For-Profit's technology centre, Ablelink¹, is based in Melbourne and is the only specialised technology training and support facility available to the Australian Deafblind Community. Ablelink has a community of about 50 deafblind participants who drop in to the centre to meet with their friends, use the Wifi and get assistance with their technology. Ongoing support is provided via email, video relay and accessible training materials.

This innovative facility has been fostering a peer training environment for many years through a collaborative model called 'iLearn Share' – a peer training model to support and encourage the deafblind community to use mobile devices.

This program aims to improve digital literacy, mental health and communication skills through peer training in the use of smart phones and tablets. Support workers, who currently work with participants in home and community access, have expanded their role to provide communication and technical support for deafblind people. iLearn Share aims to establish a community of experts sharing their knowledge and skills about mainstream mobile devices and their apps.

The initial iLearn Share project included 32 deafblind participants and 10 support workers willing to provide communication support for peer training in mobile devices. An integral part of the program is an on-loan stock of iPads and braille devices to be used at home.

The support workers were quite challenged by their changed role and the technical expertise required.

Workshops were provided for the support workers and additional training was provided individually, to improve their confidence with the technology.

The initial plan was to provide communication and technical support for peer training; however, it developed into creating a community of experts with knowledge sharing among participants, support workers and carers.

One of the big benefits of iLearn Share is that participants and support workers can share their knowledge and teach each other about adaptive technology and apps. Facebook has provided unprecedented access to old friends and extended family and through posts and comments; the deafblind community are now able to engage in conversations and exchange ideas and opinions. Support workers have been invaluable in assisting with privacy and security settings



¹ www.ablelinktech.com

Australia continued



“An integral part of the program is an on-loan stock of iPads and braille devices to be used at home”

and help with interpreting some of the comments posted.

Creating a culture of information sharing also helped iLearn Share to achieve its goals of improving digital literacy, mental health and communication skills by creating a consistent, supported environment in which participants were continually stimulated, challenged and engaged around technology.

iLearn Share helps people with their sense of independence as the timing, content and nature of their learning is entirely self-directed. The impact of this on wellbeing and sense of ownership cannot be

overstated.

Support workers were encouraged to provide feedback at monthly team meetings and training videos were created in Auslan² and uploaded to YouTube at: www.youtube.com/user/Ablelinkvideos.

Through the equipment loan program, 10 participants had access to a mobile phone for the first time in their lives and the impact was transformational. Another eight participants started learning and using braille with their devices.

The uptake of new communication through email, Facebook and SMS or Short Message Service increased their contacts,

friends, and interactions. The Australian & New Zealand Deafblind Action Facebook page has 120 members and The Usher Syndrome Support Western Australia Facebook page has 195 members.

Developing the iLearn Share model has provided many and varied insights and challenges. It was particularly surprising to see the reaction of the various support workers when providing assistance with technology given they use the same devices on a daily basis. The need for training in adaptive technology was certainly underestimated.

Most importantly, iLearn Share showed the true extent of the deafblind community's desire to engage with technology and the huge impact it has on their social life and emotional wellbeing. The independent interactions facilitated through digital literacy became a corner stone of a new found independence. Additionally the sense of community created from peer training and information sharing was palpable.

The following video is a summary of the Digital Literacy program we call iLearn Share: <https://www.youtube.com/watch?v=AVA1fFEQsXk>



² <https://en.wikipedia.org/wiki/Auslan>

Intervenor Services Human Resource Strategy (ISHRS)

The Intervenor Services Human Resource Strategy (ISHRS) is a multi-year initiative focussed on professionalizing Intervenor services, increasing the availability of highly skilled staff, and improving the quality of Intervenor services delivery to adults living with deafblindness in Ontario, Canada.

The ISHRS is a partnership between the Ontario Ministry of Community and Social Services¹ and the deafblind services sector working to ensure that deafblind services follow strong program principles and objectives, and that services are delivered in a way that is fair, accountable, financially sustainable and accessible.

What the strategy will do

This strategy will develop resources through sub-committees focussed on four key areas:

- Core Competencies,
- Best Practices in Human Resources,
- Education and Training, and
- Marketing and Communications.

It will start off by examining existing competency models within the sector

and across other sectors, as well as through stakeholder engagement with diverse audiences. It will also identify threshold competencies and define characteristics for ideal performance to determine a common set of competencies. Finally, draft core competencies models will be offered to stakeholders for input and review.

The strategy will also review current practices for recruitment, retention and future professional growth. It will identify the sector's human resource challenges through research and focus groups with human resource professionals from within the sector, and rank the challenges based on sector priorities.

Additionally, the strategy will research the existing educational programs and training pathways current Intervenor take to identify ideal learning environments to help Intervenor build for success.

Finally, the strategy will determine marketing and communication strategies to help promote the progress of the strategy across the sector and opportunities for stakeholder engagement. It will also create a website for

“Additionally, the strategy will research the existing educational programs and training pathways current Intervenor take to identify ideal learning environments”

information on best practice tools, events and professional opportunities.

What the outcomes will be

At the conclusion of the strategy, the ISHRS will increase the understanding of the sector and promote a more professional perspective of the role of Intervenor through stronger partnerships and consensus building within the sector and by leveraging key learning and ongoing liaison with other sectors.

The ISHRS will lead to highly qualified Intervenor providing quality, consistent services to individuals living with deafblindness through a clear and broadly accepted set of expectations for the role and function of an Intervenor with identifiable core competencies.



¹ www.mcscs.gov.on.ca/en/mcscs/

Canada continued

Implementation will include the following deliverables:

- Core Competencies models created to address the current and future needs of the sector with clearly defined and accepted expectations for the role and function of an Intervenor.
- A comprehensive set of best practice human resource tools and strategies for the Intervenor services sector to draw from. This will result in:
 - enhanced retention,

- increased recruitment,
- improved onboarding of highly qualified Intervenor,
- improved access for Intervenor to professional development and training opportunities that include coaching and job shadowing,
- improved access to appropriate school programs and certificates for people interested in training as Intervenor; and,

- stronger partnerships among key organizations including associations, colleges, agencies and ministries.

Individuals interested in learning more about the profession may access: information about Intervenor services, training programs and tools and guidelines at **Intervensorservices.com**.

The strategy was formally launched in Ontario on June 15th 2015.

Italy

Lega del Filo d’Oro¹

The golden thread which has helped deafblind and multisensory impaired people for over fifty years

“A precious thread linking the deafblind to the external world”!

This is the concept that inspired the name of the Lega del Filo d’Oro on 20 December 1964 when Sabina Santilli, who became deafblind at the age of 7 (through meningitis), along with a group of volunteers founded the first Italian association for the deafblind. For over 50 years now this organization has worked to assist, educate,

rehabilitate and integrate into society, a population of deafblind and multisensory impaired children, teenagers and adults.

The 50th anniversary

2014 was indeed an important year for the Lega del Filo d’Oro. During this 50th anniversary year we focused on three important initiatives: training programs for professionals, raising public awareness of the

disability and promoting options for further integration (or autonomy) of these disabled individuals into society.

The first major initiative organized by Lega del Filo d’Oro was a series of professional lectures delivered first in Ancona, followed by Rome and Molfetta, featuring Jeff Sigafoos from Victoria University of Wellington² (New Zealand), speaking about Alternative



¹ www.legadelfilodoro.it

² www.victoria.ac.nz



and Augmentative Communication³ or AAC.

Dr. Sigafoos' presentation detailed the expansion of the use of various technological aids such as Voice Output Communication Aids and various computer software programs to assist with communication. The Lega del Filo d'Oro has demonstrated that these technical aids (which have become more important in their educational and rehabilitation programs), provide acoustic and visual signals, enable deafblind and multisensory impaired persons to vocalize responses, better control their personal environment and assist in their communication with parents and others around them. These aids serve as empowerment tools, helping individuals make personal choices and decisions.

All three professional training lectures gave Lega del Filo d'Oro the opportunity to highlight its basic traditions, explain its organizational

structure highlighting its focus on education and rehabilitation.

Promoting greater awareness of the disability, the second major initiative of Lega del Filo d'Oro's celebration of its the 50th Anniversary, featured a number of projects:

- **Production of a docufilm** "50 years in the Life of a Dream Come True", directed by journalist Luca Pagliari, which included real life stories of those involved with the Association over the years including disabled individuals, family members, staff and volunteers.
- **A travelling photo exhibition** titled: "50 years in the History of Italy, Links and Highlights". This was organized in collaboration with the ANSA⁴ agency from 25 September 2014 to the 17 January 2015. The exhibit consisted of 28 panels with 164 photographs showing the key moments in the history

of Italy and the Lega del Filo d'Oro, represented by stories of deafblind individuals and their teachers, families and volunteers; actors and directors; sports champions, Nobel prize winners, politicians, saints, soldiers and workers. It showed an Italy with an interesting history of falling and rising again; feeling joy and pain, and like the Lega del Filo d'Oro, demonstrating the capability for growth and the ability to look towards new and important objectives. These photographs, looking back over the 50 years of Lega del Filo d'Oro's history, provided an opportunity to relive the Association's most important moments the past 50 years. It was another way to show the public what it means to be deafblind as well as explain the activities and projects the Association carries out to help deafblind people become independent to ensuring them a better quality of life. The exhibition can be seen on <http://mostra50.legadelfilodoro.it>

The third major initiative, promoting greater independence or autonomy of persons with deafblindness, consisted of three projects:

- **A family project.** In this project, family members (parents, siblings, extended family) of a deafblind person were demonstrated options to assist these individuals to develop their personal autonomy.

³ <https://www.prentrom.com/what-is-augmentative-and-alternative-communication>.

⁴ Augmentative and alternative communication, also known as AAC, is a term that is used to describe various methods of communication that can help people who are unable to use verbal speech to communicate. AAC can benefit a wide range of individuals, from a beginning communicator to a more sophisticated communicator who generates his own messages.

⁴ <http://www.ansa.it>



- **A self-management project.** Small groups of four or five deafblind people were provided the opportunity to experience daily living situations without any assistance from family members. The objective was to encourage the development of their skills in the home by preparing meals, caring for their personal hygiene, increasing their knowledge of their own bodies, taking responsibility for their health and beauty care, and managing their own money.

- **An experiential and sharing tutoring project.** The aim of this project was to increase the skills of the individual deafblind person through sharing experiences with other deafblind people (acting as tutors) with the intent of providing them a better perception of what it means to have an autonomous life.

The final event of the anniversary year was the fiftieth anniversary celebration held at the historic Nuova Fenice

Theatre⁵ in Osimo (AN) on 20 December 2014. This event was attended by current Association staff and volunteers, families, guests from other institutions, and the clients who performed “We Are Made of the Stuff of Dreams” dedicated to founder Sabina Santilli. This was a well-attended and emotional event which provided yet another stimulus for looking towards the future.

Future projects

There are new, important and exciting challenges facing the Lega del Filo d’Oro.

- Among them is the project to build a new National Centre in Osimo (AN), which will provide more facilities for early diagnosis and increase available spaces for clients, thus reducing the long waiting list for our services.
- There is also the commitment to open more Association offices in other regions. In 2015 a branch will open in Padova to provide local

services for individuals with deafblindness, providing them with opportunities for greater autonomy while providing much needed support for their families.

- There are plans also to increase computerization at all the Rehabilitation Centres through the introduction of an Electronic User Chart which will improve the quality of educational, rehabilitation and health processes.

The Lega del Filo d’Oro started as a small Association fifty years ago. Today it has over 500 highly trained professional staff and is represented in seven regions in Italy, with Centres in Osimo (AN), Lesmo (MB), Modena, Molfetta (BA), Termini Imerese (PA) and local offices in Rome and Naples.

For more information, contact Patrizia Ceccarani (ceccarani.p@legadelfilodoro.it); www.legadelfilodoro.it.

Photo credits: Nicolas Tarantino

⁵ http://it.wikipedia.org/wiki/Teatro_la_nuova_Fenice

Benefiting from Research:

Symposium on newly developed methods for improving interaction and communication with people with congenital and early acquired deafblindness

By: Marga Martens and Saskia Damen

During a lively symposium at Royal Dutch Kentalis¹ in the Netherlands in April this year, five recent graduated PhD students proudly presented their research projects focusing on methods for improving interaction and communication with people with congenital and early acquired deafblindness. The doctoral studies were undertaken at the University of Groningen² through the leadership of Professor Marleen Janssen. The objective of the symposium was for the graduates to inform about their PhD research results and share ideas about implementing the evidence-based methods. Within the audience were professionals who advised on some of the studies, people with deafblindness, parents, managers of various Dutch care organizations and local Dutch communities. The five studies presented included: Fostering Affective Involvement (Marga Martens), Fostering High Quality Interaction and Communication (Saskia Damen), Fostering Tactile-Bodily Interaction and Communication (Hermelinde Huisken), Motivation for Learning (Ineke Haakma), and Dynamic Assessment of Interaction and Communication (Erika Boers).

Introducing the research projects

Emphasizing the need for more research into communication in the field of deafblindness, Professor Marleen Janssen first addressed three urgent issues concerning people with congenital and early acquired deafblindness. According to Professor Janssen, people with such impairments present fundamental concerns about development and learning, social interaction and communication, and emotional and behavioral challenges. She urged the professionals and family members to make use of this new evidence-based knowledge by implementing the newly developed methods into daily practice. Following an overview of the research projects including their theoretical background presented by Professor Janssen, each researcher briefly presented their projects.

Fostering Affective Involvement³

Marga Martens investigated whether it was possible to train professionals to improve affective involvement or mutually shared emotions, to increase positive and decrease negative emotions. This

educator-oriented training builds on Janssens' former work (Fostering harmonious interaction: Janssen, M.J., Riksen-Walraven, J. M. & Van Dijk, J. P. M, 2003) which uses strategies for sharing emotions (affect attunement⁴) described in Stern (1985). It proved to be possible to increase affective involvement in eight of nine cases through coaching professionals with video feedback. In all nine cases, positive emotions increased and negative emotions decreased in the persons with deafblindness. A conclusion from this research is that challenging behavior may be prevented through the process of intervening using the process of 'fostering affective involvement'. See additional publications connected with this research topic: Martens, Janssen, Ruijsenaars, & Riksen-Walraven, 2014a; Martens, Janssen, Ruijsenaars, Huisman, & Riksen-Walraven, 2014b, c. **For further information contact Marga Martens (m.martens@kentalis.nl)**

Fostering high quality interaction and communication

Using a similar social interaction framework described by Marleen



Marga Martens



Saskia Damen

¹ www.kentalis.nl. Kentalis is a large corporate member of DbI.

² <http://www.mastersportal.eu/studies/14902/educational-sciences-communication-and-deafblindness.html>

³ Edition 53, DbI Review, July, 2014 (pp. 58-62)

⁴ The purpose of affect attunement is to share an experience of inner state between two people.

Netherlands continued

Janssen and Marga Martens, Saskia Damen was curious if it would be possible to train social partners (communication partners) to enable them to reach higher levels of communication with the congenital deafblind individuals they are supporting. Saskia developed an intervention process using the theory of intersubjective development (Bråten & Trevarthen, 2007). This theory describes the ability to share subjective states in interpersonal communication. For all 11 participants with congenital deafblindness studied, it proved to be possible to improve their communication at the two lowest layers of intersubjectivity (primary and secondary). For seven of the participants it also proved to be possible to improve communication at the third or tertiary layer of intersubjectivity. The conclusion from this work was that it was important to train social partners (communication partners) to use attunement and

meaning making methods if they were to achieve levels of high-quality communication with people with congenital deafblindness.

Additional publications connected with this research topic include: Damen, Janssen, Huisman, Ruijsenaars, & Schuengel, 2014; Damen, Janssen, Ruijsenaars, & Schuengel, 2015a, b.

For further information contact Saskia Damen (s.damen@kentalis.nl)

Fostering tactile-bodily interaction and communication

Hermelinde Huiskens' research project focused on stimulating the use of tactile-bodily interaction and communication in everyday situations. For this purpose she developed a three-phased intervention process. During Phase I, general information is provided to communication partners (of people with congenital deafblindness) about the use of tactile sign language and how this

may be applied in specific cases. For Phase II, tactile interaction is emphasized (i.e., how to tactilely initiate contact). During Phase III, communication partners are trained in narrativity (i.e., how to tactilely share attention and create opportunities for communication by creating highlights during an activity). The conclusion from this work was that it was possible to improve communication with individuals with congenital deafblindness by enhancing the tactile strategies of their communication partners. However, further studies are needed to improve this method of intervention.

For further information contact Hermelinde Huiskens (h.huiskens@rug.nl)

Motivation for learning

Ineke Haakma took a Self Determination Theory Perspective (Ryan & Deci, 2000) to investigate how students with congenital and early acquired deafblindness can be motivated for learning. This theory takes

Attendees at the Symposium at Royal Dutch Kentalis



Netherlands
continued

three psychological needs into account: Competence, Engagement, and Autonomy. Ineke was wondering how teachers addressed the students' psychological needs and how the teachers' approach affected the students' motivation for learning. It appeared that the teachers reached their highest scores through establishing Engagement with their students. The teachers scored the lowest scores achieving Autonomy. There appeared to be a high relationship between the student's motivation to learn and the teacher's level of support.
For further information contact Ineke Haakma (i.haakma@rug.nl)

Dynamic assessment of interaction and communication

To ensure high-quality communication, Erika Boers searched for ways to get a better picture of the learning potential of children with congenital deafblindness. For this purpose she developed a dynamic assessment procedure as an appropriate

approach to measure communication potential. With this approach she stayed in line with Vygotsky's idea (1978) that, to help a child, one needs to know: 1) the child's abilities and 2) how the child may be supported to enhance further development. The research project resulted in the creation of an Interaction and Communication Analysis Check List which was tested for reliability. This measurement instrument may be used in a dynamic assessment procedure in order to monitor a child's communicative development. It makes it possible to disclose hidden communication potentials.

See publication about this research project: Boers, Janssen, Minnaert, & Ruijssenaars, 2013.
For further information contact Erika Boers (e.boers@rug.nl)

Exchanging ideas

Following the research presentations, Frank Kat, managing director of Kentalis Rafael, initiated a discussion

between the presenters and the audience. The main question was how to implement the results of the studies in daily practice. Some recommendations came from these discussions, as follows:

- Provide master classes on the different research topics. (Note: According to the authors, a master class is a form of staff development (for social partners) in an academic (scientific) level. During the master class the participants receive information about the theoretical background of a given intervention; they learn how to analyze video fragments about their clients then they make a plan for intervention.)
- Develop structured coaching programs for professionals and for others (parents, etc) involved directly supporting people with deafblindness
- Establish closer collaboration with parents and family members
- Share knowledge gained during national and international events

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New Russian Deafblind Charity establishes a National Deafblind Registry

In October 2014, Russia carried out its first national census of deafblind people. The project was conducted by the newly established Charity and NGO 'Deaf-Blind Support Fund'¹ (DBSF), whose mission includes a mandate to assess the deafblind population in Russia.

Until recently, Russia did not have a definition of deafblindness in its official documents and, hence, the government had no statistics about people with this disability. References to deafblind people began to appear in early 2015, but the State Register of the Disabled had yet to recognize a category for people with the deafblindness disability.

Recognizing the need to change this situation led the DBSF-NGO to launch a census

project in collaboration with government institutions and the National Associations of the Blind and the Deaf. Together with the assistance from the Federal Ministries of Labor, Education and Healthcare, DBSF disseminated information widely to find this population. To locate these individuals, contact was made with the blindness and deafness communities; leaflets were distributed to social support workers, hospitals, clinics, boarding houses and rehabilitation centers; information was distributed through free hotline and Websites, TV ads and through social media.

A detailed questionnaire for the census was developed by experts from the field and tested first by

deafblind people to assure its appropriateness. Some ideas for the questionnaire were borrowed from the Helen Keller National Center Registry² and other international surveys. Relatively long (one would need about 40 minutes to complete), the survey contained such questions as: cause of deafblindness, languages and devices used, information about their level of education attained, working skills, hobbies, needs for assistance and support, desires for a job or self-fulfillment, etc. Once the individuals were located, professional sociologists carried out the personalized census through the assistance of the Russian Public Opinion Research Centre³, which provided its regional network



Dmitry Polikanov



Census project included meetings with people who are deafblind

¹ <http://so-edinenie.org/en/main>. The mission of the new NGO is to assess the deaf-blind population in Russia, take count of the needs and provide for improving their life standards, including their integration in social and professional activities. These efforts will be based on the best international practices and technologies.

² www.hknc.org

³ en.wikipedia.org/wiki/Russian_Public_Opinion_Research_Center

Russia continued

“We anticipate that the complete census task should be completed by the end of 2015 with implementation of the service delivery programs beginning in 2016”



to assist with the face-to-face and phone interviews.

As anticipated, the survey met certain difficulties. One impediment was the strictness of Russian laws recently adopted about personal data protection. This affected access to the official databases of some government institutions which have information already about deafblind people. Another issue is with the division of power; since most of the social, educational and healthcare institutions belong to the regional and municipal governments, they are reluctant to provide information to a federal level of authority. Other problems faced by the interviewers included: difficulty obtaining information from some deafblind people due to their communication problems; the lack of trust from their relatives about the project, poor cooperation from some

local NGOs, rumors and distorted facts about the census, etc.

To overcome some of these issues and speed up the process, the Deaf-Blind Support Fund used a business-oriented incentive program. Each deafblind person and the individual who helped locate them received a small financial aid after they completed the survey. In addition, each deafblind person was provided a free special tactile device to facilitate their communication as well as a free subscription to a special magazine for deafblind people. This special journal was created by the deafblind community and contains useful everyday information, legal advice and life stories, etc.

By late April 2015, the DBSF has created an initial database of over 2,200 entries of people with deafblindness. This data gathering census

will continue, as it is expected that as many as 12,000-15,000 deafblind people live in Russia. The big challenge now, and of course the important next step with this information is to develop individual assistance programs for all those deafblind people registered. These individuals will need training programs, family support, employment opportunities, and communication devices, just to name a few things. We anticipate that the complete census task should be completed by the end of 2015 with implementation of the service delivery programs beginning in 2016 through a ‘to-be-established’ Regional Network system.

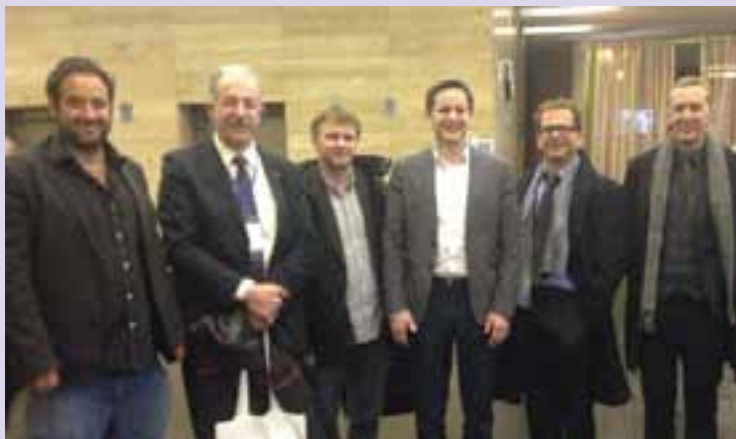
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Moscow was the site for an International Deafblind Conference

April 14-16, 2015

For the first time in many years, a large-scale international conference on deafblindness was held in Russia. Organized by the Deaf-Blind Support Fund 'Connection'¹, the conference titled "Problems of deafblind people: their experiences, problems and prospects" was held in Moscow, April 15-16, 2015. During this conference, active discussion took place about the most pressing problems affecting deafblind people in Russia and the solutions necessary for these individuals to meet their potential. Leading Russian and international experts on deafblindness and technologies aimed at the social integration of deafblind people, attended these sessions. This conference, which will become an annual event, brought together about 300 participants from 17 countries in Europe, Asia and America. Representatives from a number of the world's leading centers specializing in deafblindness, including Deafblind International (DbI), Sense International, European Deafblind Network (EDbN) and Royal Dutch Kentalis were welcomed participants.

The President of 'Connection Fund', Dmitry Polikanov, made a welcoming speech in which he noted the importance of a multidisciplinary approach to seek the solutions: "The



Presenters and dignitaries participating in the Moscow conference included: Amid Amedi, Ricard Lopez, Albin Adam, Pavel Osipov, James Thornberry and Frank Kat

conference is a first step in engaging Russia into intense exchange of the best international practices in this area. As a result, we plan to assemble the concept of the advanced applied science center and start its implementation in 2016".

Conference round-tables were designed to cover such various topics as: the definition of deafblindness; issues of education and training; developing individual's creative potential through arts and crafts, and religious care. In addition, the conference held special sessions on adaptive physical training, employment, and such technological innovations as cochlear and eye implants and various computer technological developments.

One of the eminent

guests at the conference was Professor Amir Amedi² from the Hebrew University of Jerusalem. Other neuroscientists from the United States and Germany talked about their inventions to improve the perception of visual images. For example, there was a presentation about converting an image into sound with the help of special glasses that may be attached as an eye implant.

The final stage of the conference was a seminar titled: "Deafblind 2030: the future that we choose". The leading experts tried to work out a strategy for the future and to outline the prospects of social and technological progress for the next 15 years.

For more information contact Dmitry Polikanov (d.polikanov@so-edinenie.org)

¹ <http://so-edinenie.org/en/main>

² brain.huji.ac.il/amir_amedia.asp

Russia
continued

The first Russian performance with deafblind actors was held in Moscow

The premiere performance of 'Touchables', the first large-scale theater performance featuring deafblind and professional actors, was held at the Moscow Theater of Nations¹ on April 19-20, 2015. The play by playwright Marina Krapivina² is based on the real life stories of deafblind people of various ages, as well as stories about some Soviet stars, such as Dr. Olga Skorokhodova.

The idea of this theater originally came from watching the Israeli experience. However, unlike 'Nalaga'at'³, which consists of deafblind actors only, the Russian theatre project went a step further. It attempted to ensure that the amateur actors who are deafblind

could demonstrate an equal-on-stage-performance to their professional colleagues, who included such Russian celebrities as Ingeborga Dapkunaite⁴, Yegor Beroev⁵, Anatoly Belyy⁶, etc.

Each of them told different stories through dancing, movement, pantomime, and expressive dialogues voiced in an impressive scenery using different smells, living plants, drum music and a tactile surface made of various materials (from earth and grass to metal and tiles). These different materials, sounds and smells helped the deafblind people to orient themselves on stage and understand the various breaks and scene changes.

Work on this performance began in late 2014. In October the sketch performance was shown at the International Festival of Contemporary Art School 'The Territory'⁷.

Several creative workshops grew from this theater project. On a bi-weekly basis, deafblind people (those who are actors as well as the spectators) are becoming acquainted with architecture, storytelling, music, choreography, etc. The workshops involve prominent experts from the art sphere, who devote their time for free to help these disabled individuals to feel the beauty of the world and become artists themselves.

While the performance will continue to be shown in Moscow, the Deaf-Blind Support Fund 'Connection' has a plan to structure the experience and translate it into the Russian regions where the creative groups can work in collaboration with the local theatres.

For more information contact Dmitri Polikanov (d.polikanov@so-edinenie.org).



¹ www.theatreofnations.ru/en

² cecartslink.org/residencies/open_world/theater/krapivina_marina.html

³ www.nalagaat.org.il. Nalaga'at is a small corporate member of DbI.

⁴ en.wikipedia.org/wiki/Ingeborga_Dapkunaite

⁵ en.wikipedia.org/wiki/Egor_Beroev

⁶ www.imdb.com/name/nm0069783/

⁷ www.rtlb.ru/en_festivals_item/167

ICT for people with deafblindness – a Swedish project

By Ole E. Mortensen, The Swedish National Resource Centre on Deafblindness

The speed of technological progress is increasing exponentially. Within the next seven years we will experience as much technological progress as we did in the whole of the 20th century. How do we make sure that people with deafblindness are not left behind but also benefit from this progress? A large-scale national project in Sweden is looking at that.

The Swedish National Resource Centre on Deafblindness¹ is funded by the Swedish National Board of Health and Welfare². Among the tasks given us by the Board is to identify and develop services and products for use in Information and Communication Technology or ICT.

Interviews and questionnaire

We have worked on this task beginning in April, 2014. The first step of this activity was to get a thorough picture of the situation. We interviewed all 21 county councils (who are the ones responsible for technical aids for people with deafblindness) and asked them what they saw as the major obstacles for them to make sure that people with deafblindness gain fully from the technological progress. We followed up with a questionnaire survey for people with deafblindness about their experiences with



the service from the county councils.

These two surveys told us many interesting things, but the following issues were central.

The interviews with the professionals responsible for technical aids showed that they feel a lack of knowledge on the situation of deafblindness, since only a small portion of their clients are dual sensory impaired. These professionals are either vision or hearing specialists who work with people with either vision or hearing impairment. Since people with deafblindness represent a relatively small group, these professionals do not get to meet them very often. This makes it difficult for them to build up any real expertise in this area. Furthermore they also lack the time to keep updated on the latest developments and products suitable for people with deafblindness. The questionnaire survey

showed that people with deafblindness are not overly satisfied with the service they receive from the county councils regarding technical aids. And they are especially dissatisfied with two things: the training they receive in new technical aids and the support available if something does not work.

And though this dissatisfaction is shared by the group as a whole, it is even more prominent among the sign language users.

In addition to the interviews and the questionnaire we had meetings with all other stakeholders in this matter, such the association of people with deafblindness, national authorities and agencies, researchers, suppliers, and other experts.

From this mapping we got a very accurate picture of the situation with ICT for people with deafblindness in Sweden and based upon this we have come up with three initial initiatives.

¹ www.nkcdb.se. The Swedish National Centre is a small corporate member of DbI.

² www.socialstyrelsen.se/english

Sweden continued



1. Expert advisory team

We are building an expert advisory team with two tasks: to write a monthly newsletter on new developments related to technical aids for people with deafblindness and to answer questions from professionals working with technical aids.

This means using both a push and a pull communication strategy. Each month we will push information to our subscribers providing them with news in the field as well as reassuring them that we are keeping an idea on the development for them. And our users will be able pull information from us on a need to know basis – exactly when the problem arises – which is the optimal moment for learning motivation.

The team will consist of five people with different expertise in ICT for people with deafblindness, who together cover the entire field. As I write this (beginning of June), the team has not begun its work, so I am not yet able to report on the outcome.

2. Booklet on ICT and deafblindness

We will be writing a booklet aimed at professionals in the county councils on how to

work with technical aids for people with deafblindness. The booklet will present tips and advice based on best practice in Sweden, coming from successful practitioners as well as people with deafblindness. Booklets and brochures are often not the optimal way towards changing behaviour in a group. But the purpose of this booklet is both to present practical, accessible and useful information on how to give the best service in the provision of technical aids, and to deliver a concrete and tangible object for people to keep reminding that people with deafblindness have specific needs.

3. Think tank

We want to establish a think tank consisting of researchers from universities in areas that are related to ICT for people with deafblindness, experienced practitioners and people with deafblindness with a good knowledge of technology.

This will be a Danish/Swedish collaboration and for the first meeting we will have researchers from six technical universities in Denmark and Sweden who all have worked with development projects that are or could be of relevance for people with

deafblindness. The purpose of the think tank is very simple:

There is a wealth of ongoing research on different technical topics all over the world. A lot of these projects could also benefit people with deafblindness, with or without alterations. However, it is quite certain that the specific needs of our group very seldom are being considered in these projects. The money and the research interest lie elsewhere. But if researchers are presented with examples of the challenges for our group, they may get interested and carry ideas and inspiration back to their own labs and research groups – not to mention their teaching.

We have already seen an example of this, where one the members of the think tank has introduced a proposal from me to two of his students. They are now making their master's thesis on the use of an existing technology – estimate beacons³ – fitting the needs of people with deafblindness when going shopping unaccompanied.

The first meeting of the think tank will take place early summer 2015. If it will work, only time will show! One thing is for sure: Something needs to be done in order for people with deafblindness to get on the agenda for technical research both in Scandinavia and – I suspect – all over the world. Maybe this could be a subject for international collaboration as well?

For more information contact Ole Mortensen (ole.mortensen@nkcdb.se)

³ www.estimate.com. ("Estimate Beacons and Stickers are small wireless sensors that you can attach to any location or object. They broadcast tiny radio signals which your smartphone can receive and interpret, unlocking micro-location and contextual awareness").

Exploring chances for improved participation

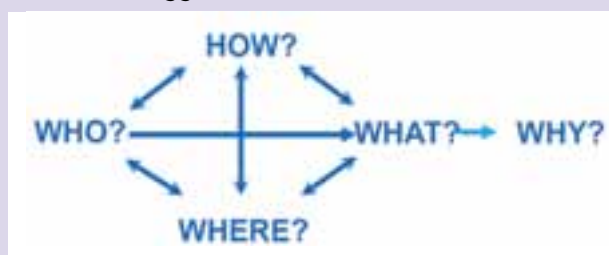
Switzerland

Tanne¹, the Swiss Foundation for children and adults with congenital deafblindness and related multi-sensory impairment, hosted the 2015 conference of German-speaking specialists in the Association for the Education of People with Visual Impairment (VBS)², June 18-20. While Participation was stated as the main theme of this international conference, the event attempted to answer: What actually does 'participation' mean?; Where, when and how is participation realized? How can participation be improved?

There is of course not just one answer to these questions. In fact to empower all persons with deafblindness (including the professionals) involves creating solutions tailored to individual situations³. To develop these solutions we need an understanding of 'participation' concepts and models to help analyze the here and now and co-create solutions for the future. In their keynote address on this topic, Professor Judith Hollenweger from the University of Teacher Education in Zurich⁴ (PH Zürich) and Mirko Baur, Tanne's Director, introduced a participation model based on the International

Classification of Functioning, Disability and Health (ICF)⁵ and the Activity Theory⁶ in its third generational discourse.

The proposed model makes the approaches defined in the participation framework of the European Agency for Development in Special Needs Education usable in our daily practice. The model translates the framework's definition, "that participation involves emotional, cognitive and behavioural engagement in activities in typical settings and routines towards a personally or socially meaningful goal" into a few very understandable questions. Those questions ask one to look at all the relevant aspects of participation in a concrete situation or, being more abstract, into the life domains of the ICF. Easily understood, this model suggests a



careful analysis, providing the necessary basis to envision an improved future with improved chances for participation.

As a tool for analysis and solutions, the model supports

the value of competent professional partners working together with persons with deafblindness.

The conference used this model as common ground in all its workshops involving learning from another and together. Tanne will continue along this path by developing a web-application for this participation model.

So after the fabulous 16th DbI World Conference in Bucharest and together with the briefly described boutique-conference in Switzerland mentioned above, staff from Tanne and other agencies are going back to our daily job: Developing better services for our clients. Tanne will continue to do this with passion and joy, at the same time grateful for the exchange of ideas and resources offered by DbI.



Mirko Baur

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Email: mirko.baur@tanne.ch
www.tanne.ch

¹ www.tanne.ch. Tanne is a small corporate member of DbI

² <http://www.euroblind.org/>

³ The individual situations of clients involves many private and professional relations and contexts, therefore the need to create solutions tailored to individual situations and systems.

⁴ <https://www.phzh.ch/en>

⁵ www.who.int/classifications/icf/en

⁶ See for example: Engestrom, Y. (2005). Development work research. Expanding activity theory in practise. Berlin (International Cultural and Historical Sciences, Vol. 25)

⁷ <https://www.european-agency.org/>

Switzerland
continued

Using objects of reference to enhance participation



Jette Hunsperger

Objects of reference are touchable objects which have an implied meaning. In the field of deafblind education they are well-known, especially to

provide information to people with deafblindness about upcoming activities, offering a way to learn to anticipate events, etc. However this involves the risk that objects of reference are only used for one-way-communication, providing information in daily routines in a rather imperative way.

As a matter of fact, objects of reference have many more communicative functions. Working on improving communication with people with deafblindness and/or with other multiple disabilities, objects of reference can be very helpful for:

- identifying their communication partner

- understanding their communication partner better
- talking about a person who is absent
- expressing wishes and needs
- making choices
- having narrative conversations about events from the past, at present or in the future
- performing activities independently
- identifying and independently finding the way to various locations.

Thus objects of reference can be important aids for individual communication and for active participation in social and cultural life. At the same time these objects support developing an understanding of symbols.

The form and use of objects of reference must always be individually adapted to each individual person together with speech or (tactile) sign language. During this

process many facts need to be considered. For more information, check out our homepage: www.tanne.ch/ newsletter.

At Tanne, the Swiss Center of Competence for the Deafblind, objects of reference are considered one of the most important aids to communication. We continually expand our treasure trove of experience and try to support other organizations through the use of objects of reference to help each individual with corresponding needs to participate fully in their social and cultural life.

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Self-regulation of behavior in CHARGE syndrome

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“Flossing teeth is not an easy habit to acquire. At least it was not for me (Hartshorne). After having to endure a bit of dental surgery due to the state of my gums, I had a new goal in mind: never repeat that. At first I hated flossing. I had to force myself every evening before bed. But my goal was strong and so I stuck with it. Gradually it became something I did pretty much automatically. Even on those late evenings when I just wanted to fall into bed, I found I could not succumb until those teeth were flossed. This is now a very well regulated behavior. My dentist is very pleased with me.”

(Tim Hartshorne)

What is Self-Regulation of Behavior?

Self-regulation of behavior is critical to development as it supports individual success socially, academically, and in everyday life. Self-regulation of behavior means having an awareness of a behavior and choosing those behaviors most adaptive

toward achieving a goal. However, what the child views as adaptive and what others in their environment would identify might be quite different. For example, a tantrum might be a great way to get what you want. The tantruming might begin out of frustration, but as goals are achieved, it can become automatic. The main goal of behavior self-regulation is to practice intentional control over behavior and eventually move to automatic regulation (Florez, 2011), as in the case of flossing teeth. In typically developing children, tantruming fades away as their goals become more complex. It is now not simply to get what you want, but to also do so in a way that does not get you in trouble too. Ideally, as the child develops, self-regulation of behavior comes to involve inhibiting useless behaviors, regulating the pace of behavior, and delaying gratification when necessary (Jahromi & Stifter, 2008).

Self-Regulation in CHARGE Syndrome

Individuals with CHARGE syndrome sometimes have an extremely hard time with self-control, seeming to lack the ability to appropriately regulate their behavior. For example, they may become

fixated on an object or thought and not be able to shift away from it, or they may not be able to inhibit an action such as throwing a toy or hitting a friend. Behavioral outbursts get in the way of an individual with CHARGE being able to perform successfully at school, form relationships, express communication, and function independently in everyday living (Lauger, Cornelius, & Keedy, 2005; Smith, et al., 2005). Treatment with psychotropic medications has become widespread, despite concerns regarding effectiveness and the lack of treatment protocols for children and for CHARGE (Wachtel, Hartshorne, & Dailor, 2007).

Hartshorne (2001) has proposed the existence of a behavioral threshold in individuals with CHARGE. There can be a very rapid change from passive to uncontrolled behavior. Hartshorne suggests levels of sensory stimulation, anxiety/stress, or pain may be responsible. However, the behavior itself can be usefully viewed as the child’s attempt to self-regulate their behavior through the pain, sensory issues, and/or anxiety. For example, Hartshorne once observed a high school girl with CHARGE on an exercise machine in the gym at her

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school. She seemed to be doing well, but then suddenly a threshold was crossed and she had a melt down and acted out aggressively. Her behavior abruptly shifted from passive and cooperative to uncontrolled. How is this self-regulation? The environment in the gym was very busy. There was loud music playing on central speakers, other students were talking loudly and traffic in front of the girl was heavy with students walking in, out, and around the gym. Her goal was to continue working out, but it was harder and harder to maintain her behavioral control. Her sensory system went into overload. Consequently, her attempts to regulate her behavior began to break down. The melt down and outburst was the last option for her, and it led to her rapid removal from that environment.

Children with CHARGE may sometimes feel hopeless and at the mercy of a chaotic environment (Janssen, Risken-Walraven, & Van Dijk, 2003). Sensory impairments and medical conditions can make it frustratingly hard to manage many aspects of their lives, and this can lead to challenging behaviors that are difficult



Timothy S. Hartshorne

to regulate. According to Nicholas (2005), the inability to self-regulate behaviors in individuals with CHARGE can be attributed to impairments in executive functioning, lack of communication skills, and sensory or multi-sensory impairment.

Hartshorne, Nicholas, Grialou, and Russ (2007) found that executive function can be impaired in CHARGE. Executive functions refer to the abilities needed to control and regulate organized behavior (Nicholas, 2005; Hartshorne, et al., 2007). This includes goal-directed behavior such as planning, decision-making, self-monitoring (ability to examine one's own behavior), self-perception (using feedback to direct behavior), and ability to make judgments (Nicholas, 2005). Common behavioral problems that arise from impaired executive functioning include: lack of impulse and inhibitory control, difficulty with mental and behavioral shifts, impaired judgment, and decreased self-perception (Nicholas, 2005), and also repetitive behaviors (Jansen, Risken-Walraven, & Van Dijk, 2003). Hence, problems with waiting one's turn to talk, difficulties in anticipation,



Jude Nicholas

and the impulsivity of individuals with CHARGE may suggest impaired executive functioning.

Sensory issues may result in many individuals with CHARGE lacking the ability to manage their threshold of arousal. They often do not know how to react to certain stimuli in their environment which consequently causes them to act out. They can often become stressed without the resources to know how to control their emotions and behaviors and calm themselves. Additionally, sensory impairment has been found to limit children's receptive and expressive communication (Lewis & Lowther, 2001), and can be linked to aggressive, self-destructive actions, and other behavior problems (Van Dijk & de Kort, 2005). Common behaviors exhibited from sensory impairments include: hitting, punching, screaming, kicking, and repetitive behaviors such as checking, counting, ordering, pacing, and hand flapping (Brown, 2005). According to Smith, Press, Koenig, and Kinnealey (2005), these types of behaviors "interfere with an individual's ability to communicate, learn and interact adaptively

“A behavior management plan should be based on an understanding of the goals or purpose of the behavior”

with the environment and are incompatible with the establishment of new skills”. (p. 419) The challenging behaviors such as tantrums, outbursts, and self-harming actions are often used because the individual does not know a different way to behave in response to a stressful situation, or is unable to communicate their needs (Van Dijk & de Kort, 2005; Smith, Smith & Blake, 2010).

Thus challenging behaviors may be adaptive responses to the situation and help the individual respond and function as effectively as they can (Brown, 2005; Hartshorne, Hefner, & Davenport, 2005). Some of these behaviors may serve as self-stimulation for the individual and can be calming (Smith, et al., 2005). Frequently the repetitive behaviors are exhibited as a tool for the individual with CHARGE to calm down and process what is happening around them (Lauger, Cornelius, & Keedy, 2005). They can help the individual to cope with their surroundings and deal with changes in their environment.

Interventions to help with self-regulation of behavior

We self-regulate ourselves in order to achieve a goal. If I want to make a friend, I have to use good social behavior skills. If I want to eat a meal, I have to engage in cooking behaviors. If I want to write an article, I have to actually write. All day long we have goals, some of which we

achieve, and others we do not. Children with CHARGE have just as many goals. A goal may be to relax, or to attend to something, or to get something they want, or to get someone to leave them alone. Not all goals are within the child’s awareness, but the behavior is still related to the goal. With the goal comes the behavior to get there. Challenging behaviors should be viewed in this context because recognizing the purpose of the behavior is the key to intervention.

A behavior management plan should be based on an understanding of the goals or purpose of the behavior. Care must be taken to evaluate and interpret the child’s behavior to have a better understanding of why and when the child engages in these behaviors (Van Dijk & de Kort, 2005; Smith et al., 2010). The context of the situation is very important. Does the child engage in certain behaviors only in particular social situations or environments? Are there anxiety-provoking stimuli that influence the child to act out in certain ways? Does the behavior seem intentional or out of the child’s control? Is the behavior an attempt to communicate wants or needs? It is also important to note what the child gets from performing the behavior or what the child is attempting to avoid by acting out certain behaviors (Bernstein & Denno, 2005). This can sometimes be identified by looking at what happens after the behavior.

Creating an ABC data chart (Antecedence, Behavior, Consequence) is one way to map out behaviors in order to evaluate them. For each behavior, what happened before the behavior (the context) and what occurred right after, are recorded. Such a chart when reviewed often reveals the purpose of the behavior and can be very useful when developing an intervention.

Simply having a goal does not by itself cause people to self-regulate their behavior (think New Year’s resolutions). They must really value the attainment of the goal. This has two important implications. The first is that in order to teach a child to self-regulate their behavior we have to convince them about the importance of the goal. Study hard so you can pass the test might be a more meaningful goal for the parent than for the child. This is why parents often have to offer incentives to make engaging in the self-regulatory behavior necessary to do well on the test more desirable (I will give you a dollar if you get an A; you will be grounded for a week if you do not pass). The point here is that if you want to teach a child to self-regulate their behavior, the child has to value the outcome or goal.

A second implication of the role of goals is that the challenging behavior children engage in is generally their attempt to self-regulate around a goal they have. For example, a child engages in

“Scaffolding describes the process of simplifying a task so that a child can perform it with support”

tantruming behavior because they do not have access to a toy that is out of reach. A second example would be a child who is experiencing gas pains frantically walks around their house, room to room, throwing objects that they encounter. They may engage in this behavior because it is only thing they have learned that helps them cope with the pain. These two examples of challenging behavior are both forms of self-regulation that allow the child to work towards their goal of either access to the toy or distraction from the pain. Of course there are better choices for behaviors that might lead to the same result, but we cannot teach these if we do not recognize that the challenging behavior has a purpose.

Thus, we want to teach the child to self-regulate their behavior in order to achieve the parent’s (or teacher’s) goal and we want to teach the child different self-regulation behaviors for achieving their own goals. The former requires making the goal important to the child, and the latter requires that we recognize the nature of the goal. In both cases, we have to specifically teach the child to self-regulate their behaviors in an appropriate and successful manner. It is generally more difficult to convince a child to change their goal than it is to teach them new behaviors to achieve it. However, many “inappropriate” goals may be

subsets of more appropriate goals. For example, disruptive behavior to get attention might be a subset of wanting to feel important and valued. If this is the case, the individual can be taught appropriate social skills so that they become more valued in the social setting.

One way to teach new behaviors is through scaffolding. Scaffolding describes the process of simplifying a task so that a child can perform it with support. Scaffolding helps the child to be able to identify the problem, learn a complex task, and control their frustrations when they do not complete the task the first time (Florez, 2011). Scaffolding involves providing enough support so that the child is able to achieve a goal or complete a task. The support is gradually reduced as the child becomes more independent (Stone, 1998). Scaffolding helps individuals use what they already know to complete tasks and learn things that they do not yet know. Scaffolding techniques include: thinking out loud, breaking the task into smaller parts, cooperative learning to promote teamwork, questioning, concrete prompts, and coaching. It is important when using scaffolding with an individual with CHARGE to monitor their stress and frustration levels so outbursts do not occur.

Teaching what kinds of behaviors are appropriate in a variety of settings is very

important. Techniques such as modeling, rehearsing, and redirecting negative behaviors to positive ones have been shown to be useful and successful (Florez, 2011; Bernstien & Denno, 2005; Smith et al. 2010). Modeling is demonstrating for the individual how to regulate specific behaviors so they can later do it independently across situations (Florez, 2011). Rehearsing involves discussing appropriate behaviors in situations beforehand. Before going to the store, discuss the behaviors that are acceptable, as well as those that are not. Focusing on positive behaviors is most effective in helping children stop their destructive behaviors (Bernstein & Denno, 2005; Blake et al., 2010). Instead of saying “no”, direct the child to alternative behaviors and habits so the person with CHARGE can exhibit them when feeling overwhelmed, frustrated, and over-stimulated. For example, teach the individual to squeeze a soft ball instead of hitting themselves or others when they are feeling upset and stressed.

Teaching choice-making skills and providing opportunities to use choice-making skills could also help reduce negative behaviors. Due to limited communication skills, many individuals with CHARGE may lack opportunities to express preferences and make choices. It is important to recognize that choices are available

and encourage individuals with CHARGE to express their preferences related to the available choices.

Parents, caregivers, and educators need to try as best they can to understand the behavioral cues the individual with CHARGE is expressing (Janssen, Risken-Walraven, & Van Dijk, 2003; Lewis & Lowther, 2001). It is important to let the child know that you understand what they are communicating. Some of these behaviors may be the only way the child knows how to convey their wants, needs, and goals (Brown, 2005). Individuals with CHARGE can become upset by change and unfamiliar situations. They may feel overwhelmed, over-stimulated, and at the

mercy of their environment (Janssen, Risken-Walraven, & Van Dijk, 2003). Therefore, it is essential to create everyday routines to make the child's life as predictable as possible. Having consistent routines reduces anxiety, as well as the intensity and frequency of challenging behaviors (Smith et al., 2010). Preparing and planning has been found to be a vital part of self-regulation (Florez, 2011). Use of a calendar system, picture board, hand gestures, and lots of verbal and visual reminders, including social stories to continually prepare the individual for a particular trip or event is extremely helpful (Van Dijk & de Kort, 2005). Scheduling sensory breaks can reduce the negative consequences

from over-stimulation, under-stimulation, and stress from anxiety-provoking stimuli in the everyday environment (Smith et al., 2005).

It is important to avoid becoming discouraged when intervening with behavior challenges. Creating a personalized intervention plan and remaining consistent is important, as is giving it time to work. Of course, the best way to reduce challenging behaviors is to reduce the stress levels of those with CHARGE. Since it can be very difficult to regulate their behavior independently, they need patient, supportive caregivers to aid them in understanding their behavior so they can learn to cope with the anxiety-provoking stimuli in their everyday lives.

Case Example

James' parents could no longer take him to the store due to his destructive behavior and meltdowns. If his mother turned her back, James might be pulling objects off of shelves and throwing them. When they passed the balloon counter, James would stand there or tantrum until his mother purchased all of the balloons. It was clear that James knew what he was doing. His behavior served to get him what he wanted, particularly balloons. He had a goal, and had chosen behaviors that were generally effective in reaching it. Trying to change the goal of a young man with CHARGE is no easy task. A different approach is to change the behaviors that led to the goal. James was provided a list of three things that needed to be purchased at the store. To begin, they were items that James liked, such as yogurt.

He was told that once these were in the cart he could have a balloon. His parents had never before seen James move through the store so quickly. A similar strategy was adopted at school where James liked to be on the computer and did not like to complete his work. His work was placed into folders that required no more than 10 minutes to complete. Once completed, he was given a token. Once he had acquired three tokens he could be on the computer. James concentrated very hard on his work. To maintain or strengthen these behaviors, you would gradually increase the challenge. His list of items to get at the store and the number of tokens needed to be on the computer could be gradually increased. But what is important is that James learned there was a way to achieve his goal through a different set of behaviors.

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Stress in individuals with Usher Syndrome type II – Results of an empirical study

by Nadja Högner

This article is a short summary of an article recently published in the *Journal of Visual Impairment and Blindness* (Högner, 2015).

1. Theoretical background

Usher syndrome (USH) is a genetic condition involving sensorineural hearing loss and degenerative retinitis pigmentosa (RP). RP leads to night blindness, low contrast sensitivity, reduced visual acuity, and concentric visual field reductions (also known as tunnel vision). Depending on the degree of hearing impairment, Usher syndrome is classified into three clinical types: USH1 is characterized by profound deafness at birth; USH2 demonstrates a relatively stable moderate-to-severe sensorineural hearing loss and in individuals with USH3, a progressive hearing loss occurs (Kimberling & Möller 1995).

The dual sensory impairment in USH leads to difficulties in many different areas of life such as communication and orientation and mobility (Miner 1995, 1997), which can significantly impair their daily life and make them more prone to stress.

Stress can be defined in a biological or physiological level as the body's response to the stress measured in the change in distribution of such hormones as adrenalin and

noradrenalin combined with reactions such as an increase in blood pressure and body temperature, with the goal to prepare the body to fight or flight (Selye 1981).

Stress can also be seen on a psychological level. In the transactional stress concept described by Lazarus and Folkman (1984), psychological stress is defined as "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus & Folkman 1984, p. 19). According to this definition, stress depends on the individual's own (cognitive) appraisal and coping skills and options. In other words, something stressful for one person may not be for another person.

Stress can have such negative impacts on individual's physical health as a decreased immune system, an increase in blood pressure or stomach ulcers. Moreover stress can lead to such psychological consequences as anxiety, fatigue, insomnia, burnout and depression (Kudielka & Kirschbaum 2002).

2. Objectives of the study

The main objective of the study was to assess stress frequency and stress intensity in different areas of the lives of people with USH. Usually

in German standardized stress questionnaires, the extent of stress in a person is assessed exclusively through determining the frequency of the stress (chronicity or chronic nature of the stress). The focus of this particular study was to also measure the intensity of the stress in addition to its frequency. According to Lazarus and Folkman (1984) stress is not only dependent on the frequency but on the appraisal of the intensity of stressor as well as the available coping strategies.

Other objectives of the study included: comparing the frequency of stress of individuals with USH to the main population; assess the relationship of such variables as age, gender and employment to stress frequency and intensity. In addition, this study provided the first time that comprehensive data could be evaluated from a large German sample of individuals with USH.

3. Methods

3.1 Questionnaires

A total of three questionnaires were used.

The first questionnaire gathered various personal information including medical reports, rehabilitation measures and available resources from the USH-patients.



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The second questionnaire, a specific stress questionnaire developed by the author, was based on to the International Classification of Functioning, Disability and Health (WHO 2001) : This questionnaire assessed stressful conditions in six life areas:

- Auditory communication (making phone calls, misunderstanding conversations);
- Orientation and mobility (tripping, bumping and orientation in the dark);
- Daily living skills (housekeeping, shopping and making meals);
- Social interactions (paternalism, pity, conflicts);
- Recreation (hobbies, sports and culture);
- Employment (understanding oral work orders, bullying and exclusion).

Participants were asked how often they experienced the stressor (frequency) and how burdensome was the stressor (intensity).

The third questionnaire used was the Trier inventory of chronic stress (TICS) , a German standardized stress questionnaire that measures

the frequency of chronic stressors with the following scales: work overload, social overload, success pressure, discontentment with work, being overwhelmed with work, lack of social recognition, social tensions, social isolation and chronic worry. With a screening scale, a general stress score can be obtained.

3.2 Sample

The study sample consisted of 262 German-speaking persons with Usher syndrome type 2 (USH2) who were primarily recruited from self-help groups as no general database exists in Germany for people with this disability.

The mean age of the sample was 51 years (range 17-79 years); 53 % were women, and 69 % were in a partnership. Although most of the study participants were highly educated, only 32 % were employed in either full or part-time positions. The participants reported receiving training programs such as: vocational rehabilitation (21 %), daily living skills (17 %) and orientation & mobility (57 %).

4. Results and discussion

The results were evaluated through statistical methods such as T-tests and One Way Anova.

4.1 Self-developed stress questionnaire

a) Reported distribution order of the stress areas.

Figure 1 (below) presents the distribution of the six stress areas, according to the mean values reported for their frequency and intensity. The six stress areas were reported in a similar descending order for frequency and intensity.

As figure 1 indicates, problems in orientation and mobility are central for these individuals, since their vision loss is not compensated through their auditory sense, which has deteriorated. Moreover, in outdoor areas orientation and mobility issues are further restricted.

b) Differences in personal variables

Age: The results indicated

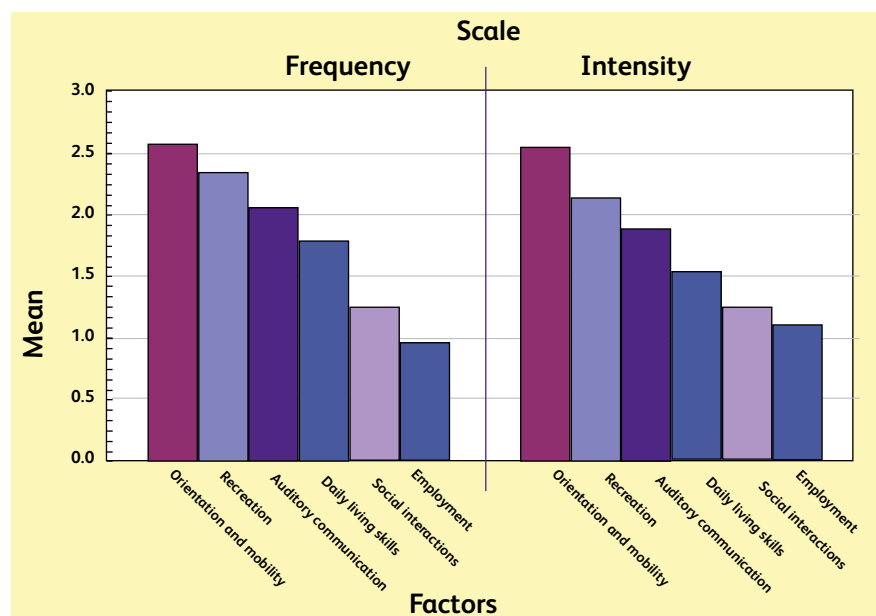


Figure 1: Reported distribution of the frequency and intensity of the stressors.

that compared to younger people, older individuals demonstrated a higher stress frequency and intensity in the areas of daily living skills and auditory communication. This can be explained by the lack of their visual field and detailed vision due to RP, making daily living and communication increasingly difficult.

Gender: Women report a higher stress frequency and intensity than men with respect to auditory communication, orientation and mobility, social interactions and employment. This is based on the greater workload experienced by women trying to manage a family and an outside job. It appears that social interactions and communication are more important for women than men.

Employment: Unemployed people report a higher stress frequency and intensity in the stress areas of daily living skills and auditory communication compared to those who are employed. Based on statistical tests, the unemployed participants reported greater impacts of their dual sensory impairment (higher hearing loss, lower visual acuity and higher visual field defects) than those who were employed. This was largely because they were older.

Partnership: No differences in stress frequency and intensity were reported between persons with or without a partner.

4.2 Trierer inventory of chronic stress (TICS)

a) Reported differences in distribution of stress frequency between individuals with USH2 and the main German population

In TICS, only stress frequency (not intensity) is measured. TICS was used to compare stress frequency of the USH2 sample (262 individuals) with the German reference group of TICS (n=604).

The results shown in Figure 2 indicate that people with USH2 demonstrate a higher frequency of stress relating to being overwhelmed with work, social tensions, social isolation and chronic worry, compared to the main population (TICS sample). In contrast, people with USH2 have a lower stress frequency than the TICS sample with respect to work overload, social overload and success pressure. The fact that most individuals in the USH2 sample were unemployed partially explains this difference. Regarding the stressors discontentment with work and lack of social recognition, no statistical differences were observed

between the two groups.

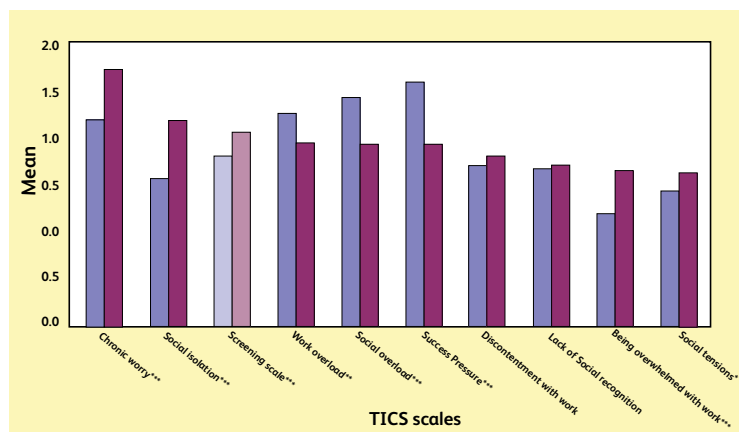
According to the stress frequency scales in Figure 2, USH2 participants demonstrated the highest frequencies in the scales chronic worry and social isolation. This could be reasonably explained by the uncertainty of the USH2 individuals about the progress of their disease, their fear of going blind and potential exclusion from society.

b) Differences in personal variables

Age: In contrast to the results of the self-developed stress questionnaire, older people with USH2 report a lower stress frequency compared to younger individuals in all of the stress scales except social tensions and social isolation. In TICS, most of the stressors can be described as work-related. Since the older people are unemployed, the stressors are less relevant to them, thus reported as lower frequencies of stress.

Gender: With regard to gender, similar outcomes are reported as in the self-developed stress questionnaire: women

Figure 2: Comparison of stress frequency between the USH2 and the TICS sample



have more stress than men (work overload, discontentment with work, being overwhelmed with work, social isolation and chronic worry).

Employment: In contrast to the self-developed stress questionnaire, employed persons in the TICS sample report higher stress frequencies (work overload, social overload, success pressure) than those who are unemployed. This is reasonable since these stressors are primarily work-related.

Partnership: With regard to partnerships, the USH2 individuals reporting not having a partner show more stress frequency in the scales social isolation and discontentment with work, because partner usually help with housekeeping, shopping, making meals etc.

5. Implications and recommendations

This study shows that

individuals with Usher syndrome display higher level of stress in different areas of their lives.

To reduce stress in people with Usher syndrome, both their internal resources (self-confidence, self-efficacy, self-esteem) and their external resources (competencies in orientation and mobility and in daily living skills) need to be strengthened. They also need to build better coping skills to work out the right coping strategies to help handle different stress situations. Therefore, stress management programs should be developed to provide successful problem and emotion-focused coping strategies. These measures should include rehabilitation programs such as training in orientation and mobility and daily life skills, relaxation techniques and techniques to improve their social and communication skills.

Due to increased competency in coping

skills, individuals with Usher syndrome may develop an enhanced sense of self-esteem and self-worth. However, to decrease the stress of social isolation, these individuals need a better access to support services and social network groups. These groups and services can provide them with a new meaning of life, through access to social activities and by social exchanges with others. This can also help to reduce the chronic worries and irrational fears by showing that life with Usher syndrome may be easier to manage when coping skills and strategies are developed.

In Germany, psychotherapeutic services have to be expanded and nationwide competency centers are needed to provide specific medical services such as diagnostics, genetic testing and rehabilitation services, as well as psychological counseling and psychotherapy for people who are deafblind.

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Acquired Deafblindness Network (ADBN)

Liz Duncan reports some exciting new developments from the Acquired Deafblindness Network (ADBN)

Acquired Deafblindness Network

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We will be launching our new membership package in the autumn. If you are a member or want to be a member of the Network, please send me your contact information and register your areas of interest. Once completed, you will receive a personal electronic copy of the current edition of DbI Review, as well as the opportunity to join webinars and discussion groups unique to ADBN members.

We are working to update the information about ADBN on our dedicated pages of the DbI website (www.deafblindinternational.org). All the information about our new plans and developments will be available there later this year.

For those of you who are wondering when and where the next ADBN conference will be, we are delighted to be working jointly with colleagues in Denmark who are organising the next European DbI Conference, planned to be held in Aalborg, Denmark, early September, 2017. This is a new approach for us all and we are very excited about the opportunities it offers.

The recent DbI world conference in Bucharest (May 25-30, 2015)



gave us an excellent programme, with lots of plenaries, workshops and poster sessions relevant to ADBN members. The venue provided an opportunity for some challenging and interesting discussions with colleagues – just what we all hope for from a conference!

For more information contact: Liz.Duncan@sense.org.uk.
Check out activities of the ADBN site: <http://adbn.deafblindinternational.org>

“The recent DbI world conference in Bucharest (May 25-30, 2015) gave us an excellent programme, with lots of plenaries, workshops and poster sessions relevant to ADBN members”

CHARGE Network

Andea Wanka reports:

It is not easy to stay connected! While this can be the case when you live with each other, or work in the same work area, but it is especially the case with our DbI CHARGE Network. Our group comprises a lot of people from different professions representing many different countries coming together for a common purpose. Some of us are fortunate to find the time and financial resources to meet at DbI or other conferences; but many don't. This high fluctuation in the numbers of people able to meet in person unfortunately does affect the stability of the Network.

http://iitf.at/wp-content/uploads/2009/10/iStock_000009588509Small.jpg



While thinking about this problem I read about "networks" and learned that a network is a system, which has a mechanism to organize itself. I'll try to be this mechanism; but admittedly sometimes it's difficult. A

lot of of elements form our network and the more connections between every member with another member the more stable it will become. So, my 58 current DbI-CHARGE-Network-Elements, let's make more connections!

Bild zeigt vier Unterarme, die sich mit den Händen gegenseitig verbinden

I wrote these words above prior to the 16th DbI Conference held in Bucharest, Romania, May 25-30, 2015.

We were provided a Network session on the last half of the afternoon on the second last day of the conference. Twenty-nine (29) people from 10 countries (Netherlands, Sweden, Germany, Norway, Malaysia, Denmark, Hong Kong, Japan, UK, USA) attended the meeting and we shared videos of children with CHARGE Syndrome and discussed on different topics. We signed up some new members, so now we have 73 members of our Network. Among a number of things we discussed during our meeting, we decided to form a facebook group to help with our communication. The facebook address is: <https://www.facebook.com/groups/>



DbICHARGEnetwork

In addition to facebook, we set up a sharing folder at www.dropbox.com and a 'what's app messenger'¹ group. The process for the latter is that individuals on the network should send their cell phone number to me (Andrea) and I will add them to our CHARGE Network messenger group. See the note below.

For more information, please contact Andrea Wanka: aw@andrea-wanka.de

Watch for the new CHARGE Network subsite on the DbI website: <http://chargenetwork.deafblindinternational.org>

¹ <https://www.whatsapp.com>

Communication Network Reports:

Applying Embodiment Theory: experiences from a two day seminar in Groningen, the Netherlands

by **Saskia Damen and Marga Martens**

This March, a two-day seminar about Embodied Cognition¹ was held at the University of Groningen² in the Netherlands. The seminar was organized by alumni of the University's International Masters' Program in Communication and Congenital Deafblindness in cooperation with the DbI Communication Network, whose members are lecturers in the program. During the two day seminar participants learned about Embodiment Theory from Professor Mark Johnson³, the author of many books and articles about this topic. During the seminar the participants applied the theory through an analysis of video-material featuring individuals with congenital deafblindness.

Embodiment Theory

Johnson explained that the assumption of Embodiment Theory is that mind, meaning, thought, and value all arise from the ongoing interactions of the body with its complex physical, interpersonal and cultural environments. The consequence of this assumption is that we should not think in terms of disembodied (or outside

the body) meaning, understanding, or reasoning. Rather, human beings are embodied human animals, and therefore all our meaning, thinking, and communication emerge from our bodily interactions with our world. Given our bodily makeup and the recurring kinds of environments we live in, various patterns in our environment afford specific possibilities for us to interact with our environment. Johnson uses the term 'Image Schema'⁴, when referring to these regular and recurring patterns. Examples of Image schema's are: balance, container, source-path-goal, up-down and near-far.

Embodiment Theory and Congenital Deafblindness

In their presentation, Saskia Damen and Marga Martens linked Embodiment Theory to the study and support of individuals with congenital deafblindness (CDB). They gave an overview of 9 Master Theses from the University of Groningen that used Embodiment Theory as a theoretical framework for the study of individuals with CDB. The overarching reason for

the use of this theory in these publications was to take into account the bodily-tactile means these individuals with CDB use to interact with the world. In contrast with seeing and hearing individuals, this way of interacting and understanding the world is much more difficult for individuals with CDB.

Ilse van Zadelhoff, a Masters Student, explained how she used Embodiment Theory in her Thesis. She made a video analysis using Johnson's theory of Image Schema's of a young boy interacting with a hot lamp.

Video-analysis

Several video clips of individuals with CDB were analyzed in small groups to see if and how the Embodiment Theory could be applied. The presentations from the groups demonstrated they had recognized Image Schema's in the interactions between individuals with CDB and their physical and social environment.

One example comes from a boy with congenital deafblindness who repeatedly imitated the down-upward movement of the zipper of his



Marga Martens



Saskia Damen



Mark Johnson

¹ <http://blogs.scientificamerican.com>. Embodied cognition, the idea that the mind is not only connected to the body but that the body influences the mind, is one of the more counter-intuitive ideas in cognitive science.

² <http://www.mastersportal.eu/studies/14902/educational-sciences-communication-and-deafblindness.html>

³ philosophy.uoregon.edu/profile/markj. Mark Johnson, Knight Professor of Liberal Arts and Sciences in the Department of Philosophy at the University of Oregon, USA

⁴ An image schema is a recurring structure within our cognitive processes which establishes patterns of understanding and reasoning. Image schemas are formed from our bodily interactions, from linguistic experience, and from historical context.



Graham Nolan presenting the results of the group assignment

bathing suit, accompanying this movement with a perfect imitation of the sound of the zipper. In this re-enactment of the closing of the zipper, a source-path goal schema was discovered.

In another video-example the development of a container schema became visible when a boy with congenital rubella syndrome was repeatedly observed pouring out liquids from a lemonade bottle and a carafe decanter into a cup. His caregiver supported his initiatives when he kept pouring in the full cup. She then invited him to touch the spilled liquid.

In both cases, as well as in other video-examples,

characteristics of the interactions between the individual and their physical and social environment played an important role in the meanings that developed. Relevant characteristics in this respect were: (tactile) access to the world, (tactile) exploration, repetition, processing time, coherency, trust, sharing of bodily-tactile experiences and development of communicative expressions that map onto bodily-tactile experiences.

Relevancy for practice

At the end of the seminar participants discussed what they had learned during the session and what they intended to bring home. They were asked to do this in several short one-on-one conversations. This 'speed dating' stimulated dynamic discussions. During the evaluation it appeared that the participants thought Embodiment Theory was a relevant theory to use in education and support for individuals with congenital deafblindness. Participants were going home with new ideas

about how to observe and support meaning making through tactile-bodily interactions. Also, for Professor Mark Johnson the seminar appeared to have broadened his personal perspective as congenital deafblindness was a new and interesting field for him. He expressed to the participants that he enjoyed very much taking part in this collaborative opportunity to apply his theory in order to develop a better understanding of individuals with complex conditions.

Next year, there will be another seminar organized at the University of Groningen. This will be a special one, since its international Master Communication and Congenital Deafblindness Program will celebrate 10 years.

Lively discussions during the 'speed dating' session



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Outdoor Network

Joe Gibson reports

This is a brief report following the DbI World Conference in Bucharest, Romania, May 25-30, 2015. The Outdoor Network had a very successful network session during the conference with 13 new members joining from five different countries. There were also several posters and one workshop focusing on outdoor activities, which was great to see. The Outdoor Network Facebook group is also growing and has been changed from secret to closed so it should be possible to search for us now!

Below is the first announcement of the 2015 Deafblind International Outdoor Week

To book a place for the outdoor week, and for more information or any questions, please contact the DbI Outdoor Network Co-ordinator Joe Gibson (jgibson@sensescotland.org.uk).

Check out: <https://www.youtube.com/watch?v=IJKakhh3SeM> for information on the Outdoor Network



Joe Gibson, Outdoor Network, Deafblind International

Deafblind International Outdoor Week 2015

First Announcement

We are pleased to announce that to celebrate the Norwegian “Year of Friluftsliv”¹ the DbI Outdoor Network Week will once again be in Norway.

- The dates are week 38 (14th-18th September)
- The location will be Sømådalen, Engerdal Kommune² (the same place as in 2013)
- The cost of the week for food, accommodation and activities will be 3000 Norwegian Kroner per person

More information to follow soon!

¹ www.mnn.com/.../how-friluftsliv-can-help-you-reconnect-with-nature. The Norwegian word, coined in 1859, has come to embody Norway’s cultural enchantment with nature. It doesn’t translate easily to English, but the basic spirit of friluftsliv hides inside all of us. Read more: <http://www.mnn.com/earth-matters/wilderness-resources/blogs/how-friluftsliv-can-help-you-reconnect-with-nature#ixzz3dug4bbnn>

² www.johnsgard.no

Research Network

Walter Wittich and Anna McGee report about the first meeting of the Research Network:



This year, the DbI Research Network was launched at the DbI World Conference in Bucharest, Romania.

Sixty-five participants attended, representing parents, researchers, practitioners, students and academics. Here is a brief summary of the results from the first meeting held during the Network afternoon.

The Name of the Network will include a subtitle in order to emphasize that this network is as inclusive as possible:

Research Network – Facilitating Knowledge Exchange among Stakeholders

The Language used within the activities of the Research Network may vary and will depend on the needs of each activity. Global initiatives will likely operate in English, whereas local activities have more flexibility and shall accommodate the needs of the individuals involved.

Content

The content of the Research Network will include anything that constitutes ‘evidence’ in that data are consistently and appropriately collected and are clearly presented as

such. This can range from case studies to program evaluations, knowledge transfer activities, all the way to experimental studies and randomized controlled trials.

Collaboration

It became clear that different needs within the Research Network would require different solutions. Therefore, the members of the Research Network will operate on a variety of web-based platforms, depending on the goal of each project:

Research Network e-mail list:

Twice per year, Walter Wittich will contact all members of the Research Network via e-mail with updates on recent developments. In order to join this e-mail group, please contact Walter Wittich through his e-mail on the Research Network web page, and request to be added to the list.

DbI Research Network Web-site page:

The DbI Research Network website page will have a section called ‘collaborative opportunities’ where members can post details of projects on which they are looking for collaboration. In order to post such a project call-for-interest, please contact Walter Wittich

through his e-mail on the Research Network web page.

Linked-In:

For those who are interested in connecting with practitioners and professionals in the field of deafblindness, Dr. Christine Marie Lehan is willing to take responsibility for the Linked-In page that represents the Research Network. An update on its progress will be sent out through the Research Network e-mail list.

Facebook:

For those interested in a less formal exchange of ideas, suggestions and discussion, Dr. Saskia Damen is willing to organize the Facebook page for the network. An update on its progress will be sent out through the Research Network e-mail list.

Thank you to those who attended the inaugural meeting of the Deafblind International Research Network. We look forward to working with you all.

For more information, contact Prof. Walter Wittich (walter.wittich@umontreal.ca) Chair, DbI Research Network.

Check out the Research site on the DbI Website: research.deafblindinternational.org

Usher Network

The Usher Network committee members have been busy thinking about how to spread the word about our fantastic network. One of our committee members, Nadja Högner, attended the DbI World Conference and chaired the Usher Network session, for which we were very proud! Her report about the session follows.

Nadja Högner reports:

We were provided two opportunities during the DbI World Conference (Bucharest, May 25-30, 2015) to discuss the Usher Network. At a plenary session, all the network leaders present (including myself) gave an update about the activities of their networks to encourage conference attendees to visit a network of their choosing on the last half of the afternoon of the second last day of the conference.

Issues discussed during our Network session included:

- A presentation about the successful Usher Preconference held in Belfast, Northern Ireland, November 2014;
- Planning for an Usher Network Preconference around the time of European Conference in Denmark, September 2017;
- Future activities of the Network, such as:
 - a) Developing the Usher site on the DbI Website – <http://usher.deafblindinternational.org>;
 - b) Informing about new developments in Usher research and outlining the need for further investigations;
 - c) Creating an international ‘chat-room’ to improve communication between people with Usher syndrome, their families and professionals;
- Opportunities to present current research results in Usher syndrome (eg., Stress and Psychosocial aspects of Usher syndrome such as Humor) at various International Conferences and events, ie presentations at the Bucharest Conference and at the International Humour Summer School in Russia in July, 2015;
- A presentation by Nadja about the way of diagnosis and support systems available for people with Usher syndrome in Germany (such as the self-help organization “Living with Usher Syndrome”);
- Participants finally discussed a wide range of the various Usher syndrome related activities going on in such countries as Sweden, Denmark and Australia. Issues/projects discussed included clinical and genetic diagnosis, data base or registration of individuals with Usher syndrome, social support services for individuals with Usher syndrome and their families, political work, self-advocacy, discussions about what services need to be improved, etc.



Nadja Högner



Emma Boswell

All in all, it was a very interesting, profitable and informative group discussion which allowed many new connections to be made. The participants will be included in the mailing list of the Usher network.

Nadja Högner
(blindenpaedagogik@googlemail.com)
For more information about the Network, contact Nadja or Emma Boswell (Emma.Boswell@sense.org.uk)

Youth Network

Simon Allison reports:

The network continues to grow in membership with many new members joining through the 'e-friends' programme. This enables deafblind young people the opportunity to develop and sustain peer group friendships through use of email. This has been particularly beneficial to young people from remote locations such as Iceland and Croatia.

The 'e-friends' programme

also linked together young people who are part of the youth network drama group. Therefore friendships were already formed prior to drama group performances. This was highlighted at the recent world conference in Romania.

During the opening ceremony on May 26, 2015, the drama group performed a short play based on the life of deafblind activist Helen Keller. Performers came from countries including England,



Simon Allison

Northern Ireland and Romania.

During the conference the network held a successful workshop session that welcomed delegates to both join the network and make suggestions for future activities. The workshop also provided an opportunity to promote the network publication 'A Glimpse of Our World'. The publication is a collection of inspirational testimonies from deafblind young people from the network.

As we look towards the future, the network is in the early stages of planning Summer Camp 2016 based in Disneyland Paris.

A consultation event will be taking place shortly to involve network members the opportunity to plan and participate in the camp

Please watch this space for further details.

Simon Allison
(Network Coordinator)

Email:
simon.allison@sense.org.uk



The poster is green and features the following text and images:

- Deafblind International Youth Network
- SUMMER CAMP 2015
- Saturday September 26th - Tuesday September 29th
- Sands Resort Newquay Cornwall England
- Full programme of activities
- Mini Conference event and workshops
- Accessible ground floor rooms
- Swimming pool and Spa
- Close to Newquay airport with connections to London
- £350 (British Sterling) Inclusive of accommodation, breakfast, evening meal, activities and hotel facilities
- To reserve a place on DbIYN Summer Camp please contact the network coordinator simon.allison@sense.org.uk

Images on the poster include the DbIYN logo (a globe with hands), an aerial view of a resort, a swimming pool, and a modern building at night.

Rubella Network

Joff McGill reports:

The Rubella Network met in Romania during the 16th DbI World Conference. The discussions focussed on the global impact of rubella with an estimated 100,000 babies a year born with congenital rubella syndrome. But rubella can be eliminated and CRS prevented, with a safe, cheap and effective vaccine either singly or in combination with a measles vaccine. Yet, the countries the highest burden of CRS lack the vaccine and in 2013 60% of children worldwide did not have access to a rubella containing vaccine.

Only a mixture of global and local action will solve this. International agencies are committed to rubella and CRS elimination which has been achieved in the Americas. The goal is to do so in Europe by 2015, and in at least 5 out of the 6 World Health Organisation regions by 2020. GAVI expect to see over 600 million children vaccinated against measles and rubella in 49 countries. 14 countries across Africa and Asian have already been approved for financial and practical support in 2014 5 countries undertook catch up vaccination campaigns.

Such work takes take political will, high levels of immunisation, monitoring



Joff McGill

and surveillance, and rapid responses to disease outbreaks. And DbI and its members have a role to play because telling the story of rubella, the impact it can have and the support people need can play a vital role in building political and public confidence in immunisation programmes.

DbI members are already engaged in this work. We heard from Edwin Osundwa, from Kenya, from Christopher Andendekisye (Tanzania), and Josephine Akiru (Uganda), talk about the children they support who have congenital rubella syndrome, but also the work they are doing with

their governments and health organisations to introduce rubella vaccination. Indeed Christopher showed a video of the recent measles/rubella catch up campaign in Tanzania¹.

It is from these countries that leadership of the world's efforts around rubella will come. But we also heard from Stan Munroe who told us about his follow up study in Canada looking at the on-going health problems people with congenital rubella experience as they grow older.

Joff McGill (Joff.mcgill@sense.org.uk)

“DbI and its members have a role to play because telling the story of rubella, the impact it can have and the support people need can play a vital role in building political and public confidence in immunisation programmes”

¹ www.gavi.org/.../Tanzania-to-protect-21-million-children-against-measles...

Online class pushes all the right buttons for Virginia teacher¹

Assistive technology class from Perkins eLearning gives one TVI innovative ideas to make learning easier for students with multiple disabilities



Shane has easier access to his CD player switch since Floyd took the class AT in Minutes

infection that causes visual impairments, as well as physical and cognitive disabilities. He's in a wheelchair, so even simple tasks like turning on a CD player

can be challenging.

Previously, Floyd put Shane's CD player on the wheelchair's tray, directly in front of him. But the confined space of the wheelchair forced Shane to twist and contort to reach the switch.

Floyd, a teacher of the visually impaired (TVI) for more than two decades, couldn't figure out a solution until she signed up for an eight-week online class called "Assistive Technology in Minutes" from Perkins eLearning³.

The class was taught by Dr. Therese Willkomm, who's been called the "MacGyver⁴ of assistive technology." Willkomm showed how to use inexpensive, everyday items to make adaptive technology devices for students who are blind or have multiple disabilities. Examples included a reaching tool made from hot dog tongs and an adapted computer mouse built from a telescoping antenna and tape.

For Floyd, the "Aha!" moment came when Willkomm demonstrated Loc-Line⁵, a flexible hose-like device made of interconnected plastic segments. It can be twisted into almost any shape.

Floyd purchased a Loc-Line and attached it to the side of Shane's wheelchair. She Velcroed a jellybean switch to the end of the hose and bent it towards Shane. Suddenly, his favorite songs were an easy touch away.

Floyd also made a book holder for Shane, and is working to adapt Loc-Line for other students who are blind with additional disabilities.

"I can mount a switch or a toy, or whatever it is I want them to interact with, anywhere on their wheelchair or on a table," she said. "It's flexible enough, yet sturdy enough that I can put a switch or something on it. And they can touch it without having to work so hard."

Floyd is also recommending the "Assistive Technology in Minutes" online class to her fellow TVIs.

"There was something new every single week (in class) that I could apply to this child or that child right away," she said. "I want to say, 'Hey, you need to know about this class because if you haven't done this yet, you definitely want to!'"

Stephanie Cloutier
Perkins School for the Blind⁶

April 15, 2015

Shane reached out and pushed a button. Country music filled the air. Shane smiled broadly, but not because he was listening to a song he loved. He smiled because pushing the button was a milestone for him.

It was also a milestone for his teacher, Lori Floyd. The adaptive technology that helped Shane play his favorite music was something she discovered at an online class offered by Perkins eLearning.

"The assistive technology (I learned) in this class lent itself so much to make things easier for these children, or more accessible for them," she said. "And it's working beautifully."

Although it seems like a small thing, being able to independently push a button is a big deal for Shane, 21, who attends public school in Henry County, Virginia.

He has cytomegalovirus², a viral

¹ Article reprinted from Perkins: In Focus, a monthly recap of the biggest news and stories

² www.nlm.nih.gov

³ www.perkinslearning.org/topics/assistive-technology. Perkins eLearning offers a wide variety of webinars and self-guided tutorials for teachers and parents, as well as online professional development classes for certified teachers. Topics include communication techniques, literacy, deafblindness and multiple disabilities, family life and more.

⁴ https://en.wikipedia.org/wiki/MacGyver (A TV series 1985-1992)

⁵ www.modularhose.com

⁶ www.perkins.org. Perkins School for the Blind is a large corporate member of DbI

Perkins International Latin America and the Caribbean Web page



See our new design, discover training through our virtual classroom and hear about some life stories that will excite and teach us...

Our website was initially created in 2010 with the aim of informing about the services offered by Perkins International through its regional offices. The intention of the website is to disseminate the most up to date information to community members involved with people with deafblindness and multiple disabilities. This information includes information about services available, recent publications from the field, success stories and details about the most advanced technology.

The format has been completely redesigned to allow users to find on the

homepage details about the history and mission of Perkins International.

The News section will inform users about events going on in the region and throughout the world and any other important facts that people might be interested in the field of deafblindness and multiple disabilities.

A “Comments” space is provided for individuals, family members and professionals to share their life experiences regarding people with these disabilities.

New sections were created, including:

“Projects” – Features an interactive map showing Perkins International support programs throughout Latin America

and the Caribbean. This section includes the list of contact persons in each country and a description of their projects.

“Life Stories” – Informative testimonials from family members, teachers and other



¹ Article ‘New Resource in Latin America’ appeared in DbI Review, Edition 47, July 2011

supporting people are shared to indicate the advances made in their learning process by specific children or youth with deafblindness and multiple disabilities. Currently on the website we share the story of Veronica and her family. Veronica gives us her observations about the years of love and significant contribution that Perkins International has offered in her life.

We invite you to enjoy your life story:
<http://www.perkinsla.org/blog-details.php?id=69&seccion=historias>



“Bibliographic Resources” – This section provides articles and digitized resources from Perkins International and other organizations providing related literature published in Spanish and Portuguese.

“Events and Courses” – Here information is shared about the availability of various courses and training opportunities offered by our partners in the region.

“Forums” – This is a section for visitors to discuss and exchange ideas on various topics of interest. Visitors can enter the site anytime to share information with other. An example that we are highlighting now is the topic ‘Rights of Persons with Multiple Disabilities’, coordinated by Massiel Requena, a leading activist mother from Venezuela.

On the website we provide a “Virtual classroom” site where we have been doing

direct online training since 2014. Currently we are offering a virtual seminar featuring Julieta Picasso, a young professional, who is sharing her testimony as a sister of a young adult with deafblindness.

We also offer through this site other courses which are of particular interest to family members and professionals. Recently over 30 individuals participated in a course on Early Literacy. We plan in the future such courses as: Basic Concepts of Deafblindness and Multiple Disabilities, Technology, Communication, Transition to Adult Life and Low Vision.

If you work or are interested in this subject and wish to know more about Perkins International, our various projects and wish to take advantage of all the resources we offer, you can access the website at: <http://www.perkinsla.org>



We invite you to join to our more than 24,000 visitors!

Social inclusion, a reality in Latin America and Caribbean

The challenge of creating opportunities to expand throughout the region

Perkins International Program

Regional Office Latin America and Caribbean

Perkins International Latin America and Caribbean has been supporting the development of accessible quality special educational programs for individuals with deafblindness and multiple disabilities throughout the Latin American region for over twenty-five years.

To achieve this goal we had to undertake several different courses of action, including:

- Identifying the training needs of professionals and providing them with the tools through participation in various educational programs geared to the special needs of their students;
- Strengthening family members to become more empowered to advocate for the educational and social rights of their family members with multiple disabilities and deafblindness, and
- Supporting the advancement of educational policies throughout the region to ensure that quality educational opportunities can be the reality for the growing number of children identified with multiple disabilities and deafblindness.

Among the diversity of contemporary social issues within culturally diverse Latin America and



the Caribbean, there is becoming increasingly revealed the individual life challenges faced by individuals with disabilities. As the number of people identified with disabilities had been growing, this has resulted in much long awaited discussion throughout the region about social inclusion within their individual communities of these people with disabilities.

In this article we share with the readers several concrete examples from the region describing positive social inclusion projects which support the right of disabled individuals to a lifestyle (with all its features of enjoyment) similar to that enjoyed by any other individual of a similar age in the community to which they belong.

Brazil pioneered this line of social inclusion practice in Latin America and for many years has demonstrated examples of best

practices from several organizations, including Abraspacem¹, Ahimsa², ADEFNAV³ and the Eva Lindstedt Centre in Santa Casa⁴. Their successful practices have included integrating children in regular schools and various 'transition to adulthood' projects. These practices in Brazil, while having a high impact in the area, also served as a model for other Perkins International programs in Latin America and Caribbean and other governments in the region.

Guatemala provides another example of best practices in Latin America and the Caribbean. Specialized care centers in this country were not always easily accessible to the children because of travel distances, thus affecting the disabled child's attendance and educational continuity. To overcome this problem for some families in Guatemala, their children

¹ Abraspacem – Associação Brasileira de Pais e Amigos dos Surdocegos e do Múltiplo Deficiente Sensorial, Abraspacem is part of Grupo Brasil (www.grupobrasil.com.br)

² Ahimsa is a small educational facility serving deafblind multiple disabled children in Sao Paulo, Brazil. Ahimsa is part of Grupo Brasil.

³ ADEFNAV (www.adefav.org.br) is an educational and rehabilitation facility for children with deafblindness, and multiple disabilities, and vision impairment.

⁴ The Eva Lindstedt Centre in Santa Casa, now 30 years old, was the first center in Brazil to provide care to low vision children and adults. The mission of the facility is to provide clinical and rehabilitation services for babies, children, adolescents, adults and elderly people with low vision, with or without additional disabilities.



The pictures show different situation where the students share the educational space and the work with the families

were integrated into regular schools with the support from the expert team working with the mainstream schools. This is another great example of a Latin American country recognizing the right to education and social inclusion for a group of its disabled population.

Part of the assessment of this social progress for these students, is the awareness this disability has created within the community, including their classmates, teachers, principals, and parents of non-disabled children. This situation has enabled these children to end their school year with positive and motivating results, especially for the organization FUNDAL⁵,

their students and their family members.

In Argentina, there are numerous excellent projects (Acipdim – IV City – Cordoba State⁶, Sullai – Cordoba⁷, Fatima – Buenos Aires⁸, South Project, La Pampa y Salta y Jujuy Project and the Outreach Project in Santa Fe) illustrating best practices examples of educational inclusion.

These successful inclusion project in Argentina were developed through the support from Perkins International and taking into account the initial successful experiences from Brazil.

The next chapter in this story for promoting the rights of these disabled individuals

is to take into full account the real needs of these people with disabilities. The challenge to us is that to carry out practices across full society current laws need to be changed.

For many years the need for training to promote the rights for disabled persons was a necessity in our region. While we have made excellent progress, much work needs to continue along this line. At the same time as we continue to strengthen these rights, it is also necessary to document the good practices according to local and international current policies.

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Davi has low vision and cerebral palsy. He attends a municipality preschooler school from Sao Paulo



Valentina goes two times a week to musical and arts classes with students at a regular school



⁵ www.fundal.org.gt (La Fundación guatemalteca para niños con sordoceguera Alex)

⁶ acipdim.weebly.com (Asociación Civil Identidades Para Personas con Discapacidades Múltiples)

⁷ http://www.institucionesullai.com (Instituto Especial para multimpedidos sensoriales y con alteraciones en la comunicación)

⁸ www.youtube.com/watch?v=tFsonim5aKU

Perkins awards Anne Sullivan Macy Medals

Recipients honored at 16th World Conference of Deafblind International
May 28, 2015

In recognition of their dedication to the international deafblind community, Perkins School for the Blind has presented three individuals with the prestigious Anne Sullivan Macy Medal.

Martha Majors of Perkins School for the Blind, Gillian Morbey of Sense International and Irina Salomatina of Usher-Forum accepted their awards at the 16th World Conference of Deafblind International in Bucharest, Romania.

They join an impressive group of past medal-winners that includes former U.S. President George Bush and first lady Barbara Bush, as well as U.S. Senator Edward M. Kennedy. The medal has been awarded since 1966 to individuals and groups around the world who have worked to break down barriers facing people who are deafblind.

Martha Majors, the assistant education director of Perkins Deafblind Program, has spent the last 40 years becoming an expert in deafblindness and CHARGE syndrome through her work as a teacher, lecturer and mentor to educators. She has traveled extensively on behalf of Perkins International, training teachers in Africa, Eastern Europe and Eurasia, Latin America and Asia. "Martha was among the first to appreciate that there was

more to it than academics," said Perkins President and CEO Dave Power, who presented the awards. "She understood that students with deafblindness needed to learn many other skills that would be important for them to become as independent as possible."

Gillian Morbey, a long-time partner of Perkins, has dedicated 30 years to the field of deafblindness. In 1985, she founded Sense Scotland, an organization that works with people who require communication support. She is currently CEO of Sense UK and Sense International, a global charity based in the United Kingdom that serves people who are deafblind in countries all around the world. In 2011, she was elected president of Deafblind International. "Colleagues know Gillian for her authenticity, her natural rapport with deafblind people and her apparently instinctive ability to see into the heart of people and situations," said Power.

Irina Salomatina is the director of Usher-Forum, a charitable organization in Moscow that supports people with Usher syndrome who are deafblind. She has worked at the Institute of Correctional Pedagogic since 1994, and has published extensively in

the field of deafblindness, particularly on research related to Usher syndrome and socio-psychological support for deafblind children, adults and their families.

The Anne Sullivan Macy Medal is awarded to individuals or groups from all over the world who have demonstrated outstanding service to the deafblind community.



Martha Majors,
Gill Morbey and
Irina Salomatina

The medal was first awarded in 1966 by Perkins in partnership with The Industrial Home for the Blind in Brooklyn, New York to recognize "the daily, tireless effort that goes into the teaching of a deafblind child during both school and after-school hours." Past recipients include parents, teachers and caregivers as well as foundations and public figures who have worked to break down barriers facing people who are deafblind.

Alix Hackett
Perkins School for the Blind

Image Close-Up Camera



Many deaf and hearing-impaired people who also suffer from sight loss have difficulty recognizing signing and lip movements at a distance of several metres. This means that they do not understand what speakers, moderators and interpreters are saying and, as a result, it is hard for them to take part in presentations and discussions.

An **IMAGE CLOSE-UP CAMERA** makes it possible to bring the image of a speaker closer and to watch the enlarged image live on a screen. Anyone who has a screen reading device with a distance camera for a whiteboard can also use this as an **IMAGE CLOSE-UP CAMERA**.

1. Tips on the set-up for organisers

- An **IMAGE CLOSE-UP CAMERA** needs an electricity supply, a table and chairs for one to three users and one accompanying person. The

position and the distances should be agreed in advance.

- The person who is speaking or signing needs to be informed about where they should sit or stand (for example, by marking the floor with sticky tape).
- The speaker should stand in front of a dark background that reaches from their thighs to 30 cm above their head (for example, a partition or a flipchart stand with a dark cloth over it).

Caution: Position the partition so that it does not block the view of the slide presentation for other members of the audience.

Additional tips for speakers

- If possible, please remain standing or sitting on the mark and do not move quickly backwards and forwards (otherwise the zoom function will take time to adjust to the new distance). It is acceptable to move a little to the left or right.
- Where there is a sign interpreter, it is a good idea

to leave enough time at the start for the camera to show the speaker and then the interpreter.

2. Tips for users and accompanying people

- Focus the camera on the centre of the speaker's body and only then zoom in or out. After this, wait until the zoom function has finished adjusting.
- Discuss with the users whether one of them or the accompanying person should use the zoom function. They should NOT use it at the same time or this will cause confusion.
- Keep adjusting the camera and focusing it on the speaker, for example when the speaker moves out of the image, when there is a new speaker or when speakers are of a different height.

Mäde Martha Müller,
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¹ <http://www.freedomscientific.com/Products/LowVision/OnyxProductFamily>

KÄNNBART



KÄNNBART *

A Swedish art project

Art has a unique ability of reaching the inner self of us. The art project *Kännbart* explores the experiences of art and communication without hearing or vision. Vision represents 80% of our senses. Hearing represents 10 - 15%. How can we work with art when these two senses are not included? *Kännbart* explores expressions together with people with deafblindness.

The target group of the exhibition is individuals with deafblindness, people with vision and hearing impairment. At the same time it is an opportunity for anyone to meet art with new senses, anyone who is interested in experiencing art in a new way.

Six contemporary artists will create six new unique art pieces. The art pieces for this project will be addressed to a spectra of senses normally not in focus at the art scene. This exhibition gives us a new form of communication and understanding of emotions through art. The art is produced with new techniques and materials exclusively for *Kännbart*. Every artist is focused on new dimensions for the experience of art; experiences without vision or hearing, the scent of art, the thought of art, the air of art and a new awareness of art. All artists work in close contact with or in collaborations with people with deafblindness to really find these new paths that have not been walked before. The Swedish Exhibition Agency (Riksställningar) provides knowledge of new possibilities in materials and techniques to new art forms and expressions.

Kännbart is a platform for communication and meetings between individuals and art. It is also a project of accessibility and democracy. Art is one of the primary foundations for creativity and insights when it comes to: what it is to be a human being? Every society needs all of us to contribute to the shared knowledge and art is a prominent factor in understanding ourselves and the world. Therefore, the group of

*Kännbart means *Touchable* in english

Secretariat News

Meetings and Elections

In May 2015 DbI invited the Management Committee and Board to come together in Romania to participate in the Outgoing and Incoming meetings for the year. It was a wonderful opportunity to thank the Outgoing ManCom and Board for their commitment to DbI. The Board reviewed the progress made over the previous four year term and agreed the group is leaving the organisation in good shape for the future Board and ManCom.

At the Annual General Meeting, the Nominations Committee announced the elected Office Bearers and the new Board for 2015 – 2019. Congratulations to all elected organisations and Office Bearers. It is exciting to welcome several new organizations to the Board who come with a fresh outlook and eagerness to further strengthen DbI. Along with the valued experience of past Board members who have been re-elected, we very much look forward to working with the new Board to progress the strategic goals, objectives and key actions of DbI. The elected Office Bearers and Board members are listed in this

issue of DbI Review and we encourage you to take a look at the list and see who you have elected to shape the direction of DbI for 2015 – 2019.

Conferences

DbI European Conference 2017

Henriette Hermann Olesen, Centre of Deafblindness and Hearing Loss,¹ presented a progress report to the Board in Romania. The conference planning committee and scientific committee have been working very hard and have made great progress so far out from the conference date. We encourage DbI members to visit the conference website (www.dbi2017denmark.com) for the latest information.

DbI World Conference 2019

In February 2014 we called for Expressions of Interest to host the 2019 World Conference. It was agreed all applicants would be asked to progress to the next round and submit a full bid. Full bids were due in December 2014. All bids were of a very high standard and ManCom recommended Able



DbI Board 2015-2019

Australia² being awarded the conference, located in Queensland, Australia. Factors that were strongly considered as part of the decision making process was rotating the conference out of Europe and towards an Asian region to encourage membership in these countries. Congratulations Able Australia!

Awards

DbI presented several awards at the conference in Romania including the new Young Professional Leadership Award. Visit the DbI website for photos of the presentations. Congratulations to all the deserving winners. If you would like to nominate a worthy person for a DbI Award, visit www.deafblindinternational.org/awards.html and complete the Awards Nomination Form.

Membership

At the DbI World Conference in Romania, DbI was pleased to have the opportunity to reconnect with many people and had the pleasure of meeting many new people from around the world. To encourage new members to become part of DbI we offered a

Board meeting 2015-2019



¹ www.dbc.rn.dk. Centre of Deafblindness and Hearing Loss is a small corporate member of DbI)

² www.ableaustralia.org.au. Able Australia is a large corporate member of DbI

special promotional membership of 15 Euros for a 2 year term. We were delighted to welcome 35 new Individual members from 18 countries including Australia, Brazil, Canada, China, Denmark, Germany, Hungary, Israel, Japan, Kenya, Norway, Romania, Spain, Sweden, Tanzania, The Netherlands, UK and USA. DbI recognises that the success it achieves worldwide greatly depends upon the support of its individual and corporate members to promote awareness and services. Thank you to all our members for your support this year. You can also visit the DbI website any time to join online at <http://deafblindinternational.org/membership.html>

On the back cover of each DbI Review the current Corporate members are listed. If you know of an organization who should be a member of DbI we would be happy to send them a letter of invitation. Please pass on any suggestions to: secretariat@deafblindinternational.org.

Partnerships

On Sunday 24th May, ManCom met with the Executive Council of World Federation of Deafblind³ (WFDB). With their Executive Council meeting in Romania prior to the world conference it was the ideal opportunity to collaborate and strengthen ties between the two organisations.

We were also delighted to welcome Chris Woodfill, Associate

Chris Woodfill speaking



Executive Director from Helen Keller National Centre⁴ and WFDB North American representative to address the Incoming DbI Board. Chris was invited to talk to the DbI Board to discuss interpreters, qualifications, training and the WFDB and World Association of Sign Language Interpreters⁵ (WASLI) Memorandum of Understanding, which is relevant to DbI. DbI will be exploring how we can work towards joint work with these two organisations.

Website and DbI Review

Continued improvements were made to the DbI website in collaboration with the Network Administrator (Paul Nobes) and Information Officer, Stan Munroe. An exciting development has been the development of individual DbI Network pages. These network pages are supported by the Network Administrator but can also be independently operated by the networks themselves. The network pages include the option of a chat room style facility and the ability for networks to upload documents such as minutes or reports. The conference guidelines

that were reviewed in 2014 were updated within the Policy & Procedure Handbook which has been uploaded to DbI website.

We love to hear from you

One of DbI's strategic goals is to encourage improvements in practice and the creation of new knowledge by facilitating improved communication and networking. So communication and the sharing of information are at the core of what we do. We would be happy to help you reach a wider audience by posting news on the DbI website or the DbI Facebook page. If you have some information you would like us to share, please contact the Secretariat and we will be pleased to see what we can do. We also have many contacts around the world and we're happy to facilitate communication so if you are hoping to connect with someone about a project you're doing but can't find who to talk to about it, just ask us!

Matthew Wittorff and Bronte Pyett
DbI Secretariat
Proudly hosted by Senses Australia



Meeting with WFDB

³ www.wfdb.eu

⁴ www.hknc.org. Helen Keller National Centre is a small corporate member of DbI.

⁵ wasli.org

DbI Board Membership 2015-2019

Management Committee

The Management Committee for the 2015-2019 period includes the two elected offices: President and two Vice-Presidents, Immediate Past President, Treasurer, Information Officer, Secretary, Development Officer and Strategic Planning Officer.



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Board Observers

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

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DbI Review – Sponsorship Guidelines



The purpose of Deafblind International (DbI) is to bring together professionals, researchers, families, people who are deafblind and administrators to raise awareness of deafblindness. Central to our work is to support the development of services to enable a good quality of life for children and adults who are deafblind of all ages.

One activity that assists in promoting the purpose of DbI is via the “DbI Review” biannual publication. This publication is coordinated and edited by the DbI Information Officer.

The opportunity should be provided to all corporate members and other organisations that support the Mission and Vision of DbI to sponsor the DbI Review. In order to achieve this, sponsorship information should be published in each edition of the DbI Review and also on the website.

Applying for Sponsorship of an Edition of the DbI Review

Applicants requesting sponsorship should have similar social values as DbI and have an interest in the well being of individuals who are deafblind.

The DbI Management Committee (ManCom) must endorse all sponsorship to the DbI Review. The Secretariat will inform applicants of the outcome of their request for sponsorship following a decision by ManCom.

Applications should be received by the DbI Secretariat. The Secretariat will then work with the Information Officer to ensure that the details of the sponsorship commitments by both the sponsor and DbI are followed through on.

Sponsorship Levels, Costs and Entitlements of DbI Review

Level 1 Sponsorship = 8000 Euro

There can be only one Level 1 sponsor. If a Level 1 sponsor is approved, then there will be no other levels of sponsorship permitted within that DbI Review edition. A Level 1 sponsor will have the following entitlements within one edition of DbI Review:

- Exclusive sponsorship rights of that DbI Review
- Name on bottom of front cover of DbI Review
- Supply photograph to be used on front cover of DbI Review
- Have input into the theme for the publication
- Full page advert
- 3 articles (related to individuals who are deafblind)
- 25 x extra copies of DbI Review

Level 2 Sponsorship = 4000 Euro

There can be only two Level 2 sponsors. A Level 2 sponsor will have the following entitlements to one edition of DbI Review:

- Half page advert
- 2 articles (related to individuals who are deafblind)
- 15 x extra copies of DbI Review

Level 3 Sponsorship = 2000 Euro

There are no limits to how many Level 3 sponsors can be approved. A Level 3 sponsor will have the following entitlements to one edition of DbI Review:

- Quarter page advert
- 10 x extra copies of DbI Review

For all levels of sponsorship, DbI reserves the right to not publish submissions that we deem for any other reason to be unsuitable, unlawful, or objectionable, such as but not limited to the content of the material (for example, the usage of inappropriate language), the subject matter, the timeliness or relevance of the material, or reasons related to intellectual property, among others.

Successful Applicants

Successful applicants will be notified no later than one month following their application submission to the publication of the DbI Review they wish to sponsor.

Applicants to accept or decline the sponsorship no later than four and a half months prior to the publication of the DbI Review.

The agreed amount of sponsorship funds will be transferred to the nominated account no later than 3 months prior to the publication date of the DbI Review they will sponsor.

Funding can only be accepted in Euros and not in any other currency.

Date endorsed by DbI Management Committee: _____

Review of guideline: 12 months after date of endorsement

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