

Dbl Review

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Cover: Transitioning at Bhakti Luher
in Malang, Indonesia

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A message from the President

Dear Friends and colleagues,

We have spent a bit of time recovering from our biggest event this year which was of course the Dbl World conference, last May in Romania. The last Dbl Review was packed full of news from the conference, so as always our job is to keep the momentum going from all the brilliant ideas we hear there.

We held our Management Committee meeting in October in London when we were able to review and catch up on a number of actions. We will be confirming these with the Board. In the meantime I can also confirm we are aware of how important Networks are to people. The other area that came out of the conference was the need to increase our diversity and representation. This has always been a challenge for us so I'm pleased that we are trying to give this more focus.

I know delegates at the conference have been following up their own actions. I am aware of at least some as both Sense and Kentalis were privileged to host Dmitry and Russian colleagues to the UK and Netherlands. I also know that the Get Out There Group or GOT group (as part of Dbl youth network) were touring Australia, so huge thanks to Senses Australia for supporting the young people to have this opportunity.

We remain in touch with our partners the WFBD and ICEVI. We are planning for the next Board to link with ICEVI's conference and meetings in Florida August 2016. No doubt Matthew is well ahead of me and our members already know.

I know the team are continuing to work hard for the next European conference in Denmark in 2017 and of course Kaye and her team at Able Australia have started the hard work towards the next World Conference in 2019.

For all our organisations it's really difficult as funding continues to be reduced. At the time of writing, the world and the context we work and live in continues to be a frightening place. I think all we can do is continue to work where we can and remain true to our values. Every small step helps in difficult times.

The Management Committee look forward to meeting our friends and colleagues at the Board meeting next summer in Orlando Florida.

With Best Wishes

Gill Morbey

President

Editorial

Welcome to the 56th Edition of Dbl Review. With each edition I continue to be amazed by the myriad of activities going on to improve the lives of individuals with deafblindness. What excites me too about this issue is the growth of science initiatives. As someone with a science background this gives me much satisfaction. The lead-off article in this edition is written by Marianne Riggio, from Perkins, titled 'Learning from the Field' represents a more detailed version of her presentation in Bucharest. As a renowned teacher in the field and experienced in international work, Marianne's article is filled with valuable advice.

Copious science related articles make up over one quarter of this magazine. This reflects a growing focus on research to assist practitioners in the field of deafblindness, as Susan Bruce explained in her article on the Action in Research Series, which begins a new Research section of the magazine.

This section includes:

- SENSE research strategy exploring the impact of deafblindness across the lifespan as described by Director of Research, Dr. Anna McGee;
- Dr. Nadja Hogner's comprehensive research on Psychosocial aspects of Usher syndrome, which is a follow-up of her paper in the previous edition documenting stress reported by individuals with Usher syndrome Type 2;
- The fifth and final article on the topic of Self-regulation in CHARGE syndrome, from Dr. Tim Hartshorne (Professor of Psychology, Central Michigan University) and his University research associates. Notable experts in CHARGE syndrome have collaborated with Dr. Hartshorne through this important series, including David Brown, Dr. Jude Nicholas, Gayle Deuce and Dr. Andrea Wanka;
- A summary report from the Canadian Deafblind Association about its recently completed 15-year follow-up results to the initial Late Manifestations of Congenital Rubella syndrome conducted in 1999, and
- an important PhD study underway examining the mental health and well being of individuals with deafblindness living in Australia.

Several scientific related articles from the Nordic Network on Cognition outline the development of assessment tools to assess the cognitive abilities of individuals with congenital deafblindness as well as measuring the cognitive decline of those with acquired deafblindness. As Network leader Eric Hans Frolander explains, new assessment tools need to be created for these individuals as the standard psychological tests developed for the regular population are not suitable for these sensory disabled individuals, some who may have other syndromes that might mask accepted testing methodologies.

From Denmark, Dorte Lindberg Jensen presents a very thought provoking discussion about important ethical considerations when working with individuals with deafblindness. Dorte Lindberg Jensen urges communication partners to respect the differences between themselves and the person with deafblindness and should

appreciate that their attitude towards life may not be the same as their deafblind partner.

As usual there are many country reports describing an array of exciting activities to improve the lives of people with deafblindness. The reports include: anniversaries (Sense's 50th and CDBA Ontario Chapter's 25th); camping activities (India and Russia); an article from Russia delving into the archives of famous Russian educators from an earlier era in the field; a synopsis about the 16th European Rehabilitation and Cultural Week for the Deafblind held in Moscow, August 03–09, 2015; a news update from the Holy Land Institute's Deafblind Unit located in Jordan; a report from the Anne Sullivan Centre in Ireland describing their busy past year and an article from Denmark describing an inclusive housing village called "The Globe", which director Henriette Hermann Olesen describes as a prime example of inclusion, a human right.

A feature article in the Country Report section is from Sense International Kenya and titled Two Voices – One Dream. Here Emma Wambui and Rebecca Murunga, in their roles as Sense International Ambassadors, use their knowledge and passion to increase support for deafblind people and their families to create change across their country.

It's always a pleasure to feature articles from Latin America. Perkins International Latin America has two interesting articles in this edition. The first one reports about their attempts to reach out to indigenous peoples living in remote regions of Latin America to provide services to those individuals identified with multiple disabilities and deafblindness. María Antonia Vazquez and Graciela Ferioli describe efforts by their colleagues to span vast geographical, language and cultural divides to provide essential services to these disabled individuals living in vastly different realities. The second article is titled International Strategies to enhance the EFAVI Campaign in Latin America, part of "Education For All children with Visual Impairment" – a global program of the International Council for Education of People with Visual Impairment (ICEVI), acting in partnership with the World Blind Union (WBU) and backed by UNESCO and UNICEF.

The Dbl Networks continue to demonstrate strong levels of activity. The Youth Network's 'Got to Act' players followed up on their performance of the Helen Keller Story at the Bucharest Dbl Conference with another performance during their visit to Senses Australia in Perth. The vibrant Outdoor Network reported a successful International Outdoor Week this past September in Norway. The Communication Network was in a celebratory mood this past November with their announcement of the first volume of their online journal: Journal of Deafblind Studies on Communication. Riitta Lahtinen and Russ Palmer from the Social Haptic Network reported on their activities including experience with haptics in various hospital settings.

Finally, this edition features an article from two teachers in Denmark inquiring how to create an innovative and exciting teaching environment to inspire students with deafblindness to participate in sporting activities, make new friends across various levels of function and develop communicatively. Their answer is APA: Adapted Physical Activity, a method which

brings joy and pleasure to physical education, allowing students to experience independence, empowerment and equality regardless of their level of function.

Thanks again to the many contributors for sharing your projects and advice to the rest of the world. Keep the articles coming!

Respectively,
Stan Munroe

Vice Presidents' Messages

Bernadette M. Kappen reports:

The 2015 year for Dbl has been an exciting one. The World Conference in Bucharest was an opportunity for individuals to meet and share knowledge as well as joining with colleagues from the World Federation for the Deafblind (WFDB). This partnership is so important to the work of Dbl. Many of the members of Dbl are working with children and young adults and the connection with WFDB helps bridge the gap from school to adulthood.

In every field, professionals are talking about succession planning. Dbl is no exception and seeing three young professionals receive awards at the World Conference helps us look to the future and the continued growth of Dbl. The Young Leadership Award was presented for the first time in Bucharest and I encourage you to consider nominating a deserving individual for this award. As a professional, please talk to others about your work with individuals who are deafblind and help them see that working in the field is one of the best jobs anyone could have. We need to continue to bring qualified individuals into the lives of people who are deafblind.

Bernadette M. Kappen
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Frank Kat reports:

Following the Bucharest Conference, there were several changes in the composition of the Board. This presents the perfect moment to ponder our strategic decisions and direction for the coming years, matters that we already touched upon during our meeting of the new Board in Bucharest. These were also some main points discussed at the recent meeting of Management Committee in London this past October.

I believe that Dbl is a unique organization; one with great potential. In addition to organizing conferences and meetings and facilitating Dbl networks, Dbl is primarily a group of people who have a great deal to share with each other. Through our meetings and conferences we transcend institutions' and organizations' interests to

achieve common goals. I should therefore like to use this opportunity to encourage all members (board members, network members, etc.) to use Dbl as the opportunity to share. You and your organizations are great sources of expertise, experience and passion. Our networks and conferences are places where you can find each other to talk about challenges, issues and solutions, but we should also be finding each other throughout the year.

Let us resolve to use this enormous network more often, to query each other and exchange knowledge and ideas, perhaps about recent studies, technical and medical matters and practical matters of education. Let's make a deal that any opportunity to support one another is used openly.

I could name a few countries where changes in the financial climate have made it necessary to make challenging decisions that have a large impact on deafblind people's support. But I also know that all supporters, experts and organizations are looking for solutions. Wouldn't it be fabulous if we shared more of this together? And this could be so easily achieved! On the back of each Dbl Review there is a list of names and email addresses. Send a message, arrange a Skype meeting, let's keep meeting with each other.

The future belongs to those who believe in the beauty of their dreams (Eleanor Roosevelt)

Frank Kat

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Learning from the Field

Marianne Riggio, Perkins International

Many international development programs are based in countries where there are comprehensive laws that mandate education for all children, regardless of their disabilities. The countries they serve are not always so fortunate.

The United Nation Sustainable Development Goals¹ give every country the aspiration to: *ensure inclusive and equitable quality education and promote lifelong learning opportunities for all*. Achieving this goal for children and young adults who are deafblind is a great challenge since more than 95% of this population is currently left out of educational services.

International Non-Government Organizations (INGOs)² who have the mission to support efforts in countries around the world where education for all children is not yet a right have a lot of work to do but must proceed with care. Often times we operate from the framework of our own experiences, imposing our own country models in places that have a very different landscape and culture.

We need to understand the reality

The early pioneers in our field like Jan van Dijk³, developed approaches for educating children with congenital deafblindness that were very much grounded in our ability to join them and try to understand their perception of the world.

While the population of children with deafblindness has changed, from the days of Helen Keller and Laura Bridgman⁴ to children born during the rubella epidemic over 50 years ago to the new generation of children with CHARGE and other very unique and complex diagnoses, it reminds us that **we must reevaluate the reality of each child every day**. Even though it is not totally possible, we must try to step into the experience of our students and how they perceive the world. By doing so, we will find the best ways to communicate together and to create meaningful learning opportunities that will open up the world to them.

In professions like law, medicine and education, certain fundamental practices that are at the core do not change. When we think back to the days of Helen Keller and Anne Sullivan, we are reminded that no matter how advanced our thinking becomes and how advanced the technology, we must still first build a relationship with our students and provide ongoing opportunities to build direct social communication – Just the same as mothers and their infants have always done.

Our interactions with people who are deafblind are very personal. We would not cast off these core elements but rather enhance them by coming up with creative ways that will broaden their life possibilities. An example of this can be seen in the technology that has enabled people who are deafblind to have the same access to internet communication as people who are sighted and hearing. What a boon this has been in minimizing isolation for so many.

Throughout the years, the work of Perkins International⁵ and other INGOs⁶ in the field have sought to help find those local solutions to challenges faced by individual programs and the larger systems that serve children who are deafblind.

The pioneers of the work everywhere in the world were teachers and parents who operated on their own passion to offer access to education for children who are deafblind. Many began with no formal training but knew it was the right thing to do. Many had acquired information in a variety of ways and have encountered incredible challenges in their path. We should all be inspired by these individuals who have really shaped all of the work in our field.

Even today, where services are still being developed we have to open ourselves to the realities of these countries before we jump to help them. We must immerse ourselves into the life of individual schools and cultures with very few resources. At times it seems daunting, but this process provides us with the valuable opportunity to live the reality and help work out solutions that will be meaningful. It is a very enriching experience to step away from all of the material and professional resources that are available in developed countries and step back into the core of what it means to teach children with deafblindness.

As we support our colleagues in the development of services, our role becomes one of encouraging them not to try to replicate schools from the west, but in a way, give them permission to draw from the richness of their own surroundings and cultures. When we try to replicate our own systems in another culture, it often just doesn't feel right. An example can be seen in a deafblind unit near the coast of Kenya. In the

Kenyan culture festive music and drumming are part of their traditions. We needed to let the teachers know that it was ok to bring music and drumming into the classroom. Once the drums were brought into the otherwise quiet classroom, circle time came alive and staff and students were fully engaged and happy.

One of the great challenges for children who are congenitally deafblind is in understanding the world that surrounds them. The strategy of teaching in natural environments and keeping to the pace of our students and having them fully participate in every activity are considered best practices that sometimes are difficult to embrace in modern western schools where the pace is more hurried.

As we support schools, we come away reminded that sometimes a little bit less can be more – as long as it isn't too much less – and as long as teacher and parents are given appropriate training and support. Often, teaching children in natural environments is the only option. Teachers cannot afford specialized teaching materials. They cannot use commercially made materials that often don't exactly meet the specific learning style of a child. There is no rush to keep a tight schedule of classes so teachers can adjust their pace and ensure that children have the time necessary to fully participate in tasks.

I would like to share an example of how our partners, with our support have managed to provide very meaningful education for their students. At Bhakti Luher in Malang, Indonesia⁷, there is no Walmart, rather, there are often small kiosks in villages where people buy their food and household supplies. At this longtime partner of Perkins International, the children learn many skills through the real life practice of making items such as shaved ice and snacks and selling them every day within in their community. They are providing a real service that makes them valued members of the community, while they are learning valuable social communication and independent living skills, concepts, and a sense of belonging. They are also bringing in financial resources that help defray program expenses.

In order to support the growth of high quality educational services we all must be challenged to go to the next level. The next level comes from building communities of practice where professionals and families alike can come together to build their own momentum and evolving best practices. An example of this can be seen in Voice and Vision in India⁸, where professionals from programs around the country have joined together to train teachers, families, and CBR workers in addition to developing culturally and linguistically accessible materials.

There has been much debate in the field of international educational program development about the merit of bringing teachers out of their own environment for training. It has been our experience in working with the Educational Leadership Program⁹ that bringing people outside their culture to see mature multifaceted educational models has the benefit of giving an already good teacher confidence and additional competence to critically think about how to take their programs to that next level and to think outside of the box about creative solutions to the challenges in their home countries.

Another example in Latin America, Perkins International in partnership with the Catholic University of Cordoba (Universidad Católica de Córdoba)¹⁰ has addressed the worldwide challenges of transition to adult life through an international online

training course that brings together parents, professional, employers among others that will to push their systems to come up with creative solutions.

Reaching the Unreached

In order to establish services for children and young adults who are deafblind, understanding the landscape is crucial and no one understands the situation better than those who live there. To do this I want to share a couple of stories of places where we have worked that exemplify how we must work within the reality of our partners.

Some of you may be familiar with Community Based Rehabilitation (CBR)¹¹. It was first initiated in Asia thanks to the work of Bob Jackle of CBM (Christoffel Blindenmission)¹². Simplistically, CBR is a model that was developed primarily to help adults who are blind establish themselves as working and contributing members of their home villages. The CBR worker helped the person who they were serving settle in meaningful work, gathering the support needed from their family and other members of their community who would receive training.

This idea of reaching out to people in their home communities caught on like wildfire throughout Asia and is spreading into other regions of the world. In the process it has also been modified to meet a broader need.

As people in the blindness field saw the reach and value of the CBR model, it was adapted by visionaries such as those at Blind Peoples Association (BPA)¹³ where a group of visionary professionals had established a school program on their campus in Ahmedabad for children with multiple disabilities but they faced many challenges. One of the big challenges was finding children in remote areas of Gujarat and providing them with needed services.

Through the wisdom of the BPA leadership they decided that they needed to train CBR workers in the basic competencies of working with children with multiple disabilities so those people could identify children in the subregions of Gujarat and then work with their families to provide learning opportunities.

These CBR workers began to carefully document information about the children with multiple disabilities and worked in defined areas to offer guidance and support including their goals and results. Their presence in often extremely remote villages drew attention and support to the needs of the children.

In one Jain community where BPA had a presence, the project, brought to light the needs of children with multiple disabilities and resulted in the donation of a place in the temple compound where children with disabilities and their families could meet together and receive services. The same held true in other communities and gradually, with some support from government, what came to look more like school programs began springing up around Gujarat. When children attended these programs, small and informal parent groups began to also emerge.

In the Philippines, where many children are also served using the CBR model, PAVIC¹⁴ which is the very strong organization of parents of children with visual impairment identified the lack of availability of trained occupational and physical therapists as a significant problem and as parents will do, they found a creative way

of solving it. They brought families together on family weekends where therapists could evaluate children and then show their families what they could do at home.

Working in Children's Homes

In many parts of the world, there is very little support given to families with children that have disabilities and particularly those with deafblindness and multiple disabilities. In part, this is due to the lack of awareness in medical communities but also from the lack of financial resources to support comprehensive early intervention, school and adult services. This has resulted in many children being placed in children's homes. It is often the perception that children's homes or orphanages just provide care and not education.

Leaders of children's homes in Eastern Europe, Russia and other parts of the world have proven this notion very wrong. These people have shown their commitment to offering high quality educational services and have become the centers of excellence in their countries in the education of children with deafblindness and multiple disabilities. They have reached out to engage families in ways that will encourage them to keep their relationship with their children. They run family camps and support family networks. In addition, many are beginning to provide direct early intervention services so children will have a stronger likelihood of remaining in the care of their parents.

These are just a few examples of the ways that people have just worked with what is their reality and found the most dignified of solutions. For those who are lucky enough to be in positions where they can support and offer guidance in the development of services for students with deafblindness, keep your ear to the ground and learn about the culture and landscape; keep the fundamental values that you hold firm, but also keep an open mind to the possibilities that suit the culture; help facilitate the dialogue about needs and solutions – you will learn a lot; finally be a catalyst to helping partners find creative solutions to challenges that will take them to the next level.

Marianne Riggio
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¹ (Goal 4) <https://sustainabledevelopment.un.org/sdg4>

² <https://en.wikipedia.org>

³ www.drjanvandijk.org

⁴ www.perkins.org/history/people/laura-bridgman

⁵ www.perkins.org. Perkins School for the Blind is a large corporate member of Dbl.

⁶ https://en.wikipedia.org/.../International_non-governmental_organization

⁷ <http://www.bhaktiuhur.org/category/berita/malang-pusat/>

⁸ [Perkins](http://www.perkins.org) National Resource and Training Centre for Children with Vision Impairment and Multiple Disabilities, including Deafblindness. (www.voicevisionindia.org)

⁹ www.perkins.org/international/elp. The Educational Leadership Program is Perkins International's flagship teacher training program.

¹⁰ www.ucc.edu.ar

¹¹ https://en.wikipedia.org/wiki/Community-based_rehabilitation. The aim of community-based rehabilitation (CBR) is to help people with disabilities, by establishing community-based programs for social integration, equalization of opportunities, and rehabilitation programs for the disabled.

¹² CBM is a large corporate member of Dbl.

¹³ www.bpaindia.org

¹⁴ Parent advocates for the visually impaired children (icevi.org/publications/educator/.../educator-july-december_2002p15.htm). <https://www.facebook.com/Parent-Advocates-For-Visually-Impaired-Children>

Ethics, partner competence and congenital deafblindness

Dorte Lindberg Jensen

“A person who is severely impaired never knows his hidden sources of strength until he is treated like a normal human being and encouraged to shape his own life” –Helen Keller, 1955¹.

“A person never deals with another human being without holding some of its life in his hand” –K.E. Løgstrup, 1956².

These sixty year old quotes by Keller and Løgstrup are as valid today as they ever were, not least when it comes to the ethical challenges inherent when working with people with congenital deafblindness. Having worked with adult people with congenital deafblindness for several years I find it very interesting how the concepts of partner competence and ethics unfolds in my work and how the concepts invites such thought provoking questions as: How can I give the person with deafblindness the opportunity to make their own decisions when it is so problematic for them to express their wishes and dreams? How do we place ourselves as caregivers together with the one who needs support in such a way that as a competent partner I am able to contribute to an environment characterized by equality and appropriate ethical relations?

This article attempts to explain how ethical considerations can be a beneficial extension to the concept of partner competence and how this ethical perspective can create a reflective environment through sharing thoughts with colleagues working with people with congenital deafblindness.

Partner competence

According to the Norwegian psychologist Per Lorentzen³, one must try to organize situations in a way that the other person succeeds. Such an approach can be a useful starting point when staff supporting people with congenital deafblindness considers how they can become a competent communication partner. What characterizes a successful communication partnership here is twofold: that the relationship between the staff member and the person with deafblindness is recognized as equal, and that each of the partners have resources that the other person can benefit from. In this regard, the basis of the partner competence is equality, reciprocity, recognition and fellowship; all concepts which help build the relationship between partner and the person with congenital deafblindness. When working in Denmark around congenital deafblindness, the dialogical perspective is very important. Dialogue here contains three elements: Oneself, the other person and the relationship between them. The Language created in this relationship is context-sensitive, i.e. depends on circumstances: By doing something

with another person we learn the language that goes along with this specific act. This develops the sense of self and identity.

The American psychologist Jerome Bruner⁴ has said that knowledge is created through dialogue, negotiation and fellowship. With this in mind, the partner can take a narrative (person centred) approach to his work, by putting a large emphasis on creating and telling stories together with the person with deafblindness. Through this approach the person with congenital deafblindness is able to create Body Emotional Traces (BET's)⁵ which are preserved in their memory. Another angle is working with reciprocity; in this approach the focus is on listening, understanding and acknowledgement, which helps create an equal relationship between the partner and the person with deafblindness.

Ethics

Ethics primarily concerns the personal reflections one has in relation to specific choices and actions, and the standards and values that they are based on. In a specific situation ethical responsibility is always personal, because it is oneself who determines if an action, and therefore the relationship between the partner and the person with deafblindness, is ethically sound.

The driver in the ethics of care is the sympathy and the empathy with the fellow human⁶. For the partner, this entails both the empathy for the person with deafblindness, and the ability to take appropriate actions. In this matter, Per Lorentzen (2011) notes, that it is the interaction between people that allow ethical actions to occur. This however demands an open minded approach and an active response. Henceforth, listening, understanding and responding appropriately are key factors in acting ethically. As this shows, ethical thinking is strongly related to the dialogical perspective, which often is regarded as a cornerstone in the daily work with people with congenital deafblindness.

Dilemmas according to the dual sensory loss

Several dilemmas exist in terms of working with people who have a dual sensory loss. In the ethics of care, sympathy and the empathy are important issues. The competent partner of course tries to empathize, but can he really relate to the life of a deafblind person? The partner's task is to obtain knowledge about the severity of the person's dual sensory loss. Does the person with deafblindness use part of his hearing or sight, or is touch their primary sense? This is an important question, the answer which helps the partner empathize with the other person.

According to the ethics of proximity, we need to ask ourselves how we should act responsibly regarding the person with deafblindness considering that his life is so different from ours (Per Lorentzen, 2011). In this regard, it is important that the communication partner respect the differences between them-self and the person with deafblindness and appreciate that their attitude towards life may not be the same as the other person. The responsible action then is to respect the initiatives of each other and together try to find a common way of communication.

To create a reflective environment

Ethical interactions that are undertaken between the staff member and the person with congenital deafblindness should be based on the choices that the deafblind partner makes in specific situations. At the same time the communication partner is a member of staff who together with his colleagues are employed to create a supportive environment for the people with deafblindness. Because of that, there needs to be an open and reflective approach to ethical questions not just by the individual partner as such, but by the institution as a whole.

In my understanding, it is important to share mutual values with my colleagues on ethical questions. If we want mutual values in our staff group it is important to discuss and reflect upon ethical questions. According to Per Lorentzen (2011) these ethical choices are always personal; but in a staff group it is important to have a common understanding.

In this way an ethical perspective can be seen as an extension of the partner competence, where the partner makes an ethical choice based on knowledge and professional insight. By doing this, the competent partner helps create a reflective or thoughtful environment for how to work with people with congenital deafblindness.

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¹ www.afb.org

² From the book by K.E. Løgstrup: 'The Ethical Demand (Den Ethiske Fordring)' originally published in Danish in 1956.

³ Taken from the book by Per Lorentzen: "Ansvar Og Etik I Socialpædagogisk Arbejde", 2011. Publisher: Akademisk Forlag

⁴ "Teorier om læring" by Tom Richie, 2010. Publisher: Billesø og Baltzer

⁵ www.deafblindinformation.org.au/congenital.../for.../communication

⁶ The reference is taken from the book "Ethiske teorier" by Associate Professor, Jørgen Husted (Aarhus University, Denmark). Published, 2014 by Hans Reitzels forlag.

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CHARGE Network

Andrea Wanka reports:

Thoughts and insights from the Dbl CHARGE Network

- Children with CHARGE will often do things differently – it is important to acknowledge and celebrate these.
- Pick your battles – they will often be able to hold out longer than you can!
- If there is a change in behaviour make sure the child is checked by the doctor in case something is causing them pain!
- The child is a child first and not a condition!
- They are amazing!
- Develop your diplomatic skills and be prepared to bargain and negotiate.

Personal collection

- Provide structure
- Give personal space
- Wait after giving new information
- Be aware of your position
- Be aware of sensory preferences
- Use positive language and be aware of trigger topics
- Use specific words for specific situations (to be sure it's clear and not confusing)

Additional questions to the personal collection

- Is the other one ready to receive information?
- Is it clear what can be expected from the other one (trustful relationship)?
- Can we be sure that we are talking about the same; that we're both knowing what is meant?
- Reflect the use of functional behavioral analysis to support professionals to determine the causes of anxiety in children with CHARGE
- How may the principles of Positive Behavior Support (PBS) and modified Cognitive Behavior Therapy (CBT) apply to the relief of anxiety driven compulsive behaviors and aggression?

For more information, Contact Andrea Wanka
(aw@andrea-wanka.de) and check out
<http://chargenetwork.deafblindinternational.org>

Communication Network

Conference journal report

Ton Visser reports:

First Academic Journal on Deafblindness published

Through the initiative of the University of Groningen's Marleen Janssen's, a member of DbI's Communication Network, the first volume of the *Journal of Deafblind Studies on Communication* was published on Thursday, November 19, 2015. The journal is the first academic journal on deafblindness in the world and will be published in an open access format. The journal is aimed at students and professionals, and contains theoretical articles, evidence-based methods, and best practices.

Demand for knowledge from the field

"We receive a fairly constant stream of questions from the field about the research from our Masters students", says Marleen Janssen in response to the question what motivated the launch of the journal. She established the journal in cooperation with the *DbI Communication Network*, a group of experts from around the world in the area of deafblindness. The Network also acts as the journal's editorial board. "The Network decided to go for a journal instead of a book. Additionally, by opting for an open access format, the knowledge and insights will be accessible to anyone across the globe", says Marleen Janssen. The journal will be addressing those in the field as well as researchers from other specialties who research the complex communications among those with a communication disorder.

First volume launched on November 19, 2015

The first volume of the *Journal of Deafblind Studies on Communication* was launched Thursday, November 19 during a meeting of the *DbI Working Group on Communication (also known as the Communications Network)* in Groningen, the Netherlands. During this meeting, the group started laying the groundwork for the second volume, which will be published in 2016. The Network is preparing for a conference to celebrate the 10th anniversary of the University of Groningen's unique Communication and Deafblindness Masters program.

University of Groningen Library

The *Journal of Deafblind Studies on Communication* was developed in close cooperation with the University of Groningen Library. The technology to publish the journal in an open access format was developed by the library.

The URL of a new open access journal: The Journal of Deafblind Studies on Communication is: jdbsc.rug.nl

For more information, contact Ton Visser (asmvisser1948@gmail.com) or Marleen Janssen (h.j.m.janssen@rug.nl)

Conference on Communication and Congenital Deafblindness

First announcement

On the occasion of celebrating ten years of the International Masters of Education in Communication and Congenital Deafblindness at the University of Groningen¹ in The Netherlands, the University will host a conference in 2016. The programme for the conference will be prepared by the Dbl Communication Network² in collaboration with the alumni of the University of Groningen Masters program.

Date: November
15–17th, 2016

Location: University of Groningen, The Netherlands

Title: Communication in the context of congenital deafblindness: ten years of studies on how knowledge and practice develops.

More information will follow.

¹ <http://www.rug.nl/masters/communication-and-deafblindness>

² <http://communication.deafblindinternational.org>

Outdoor Network

Joe Gibson reports:

The Dbl Outdoor Network continues to grow with a membership of now over 100 members on the e-mail list and representing 21 different countries. A new development is the Outdoor Network Facebook page which currently has 60 members (<https://www.facebook.com/groups/771554296237459>).

People are now beginning to share their experiences on the groups' Facebook page which is a good way to keep in touch with other people interested in the outdoors. This past September the annual meeting of the Outdoor Network occurred in Sømådalen, Norway¹ where we celebrated the Norwegian year of Friluftsliv². The theme this year was 'food' and the group caught, cleaned, cooked and ate fish from the lake. They also had the opportunity to collect and prepare vegetables and herbs

that were used in the final meal. We also travelled by canoe to a nearby beach and had the chance to put up tents and spend the night sleeping on the beach. We are hoping for an early announcement of the 2016 outdoor week soon!

For more information, contact Joe Gibson, Dbl Outdoor Coordinator (jgibson@sensescotland.org.uk). Also, for further information about the network check out <http://outdoornetwork.deafblindinternational.org>.

¹ www.visitnorway.com

² Friluftsliv is a Norwegian word loosely translated as "open air life," which characterizes Norwegian culture

First Announcement of the Deafblind International Outdoor Network's annual meeting for 2016

This is an early announcement of the Dbl Outdoor Network's annual meeting for 2016

- In 2016 the week will be held during week 37 (12th–16th September)
- For the first time the outdoor week will be held in England hosted by Sense
- We will be based at the Calvert Trust – Exmoor, in the south west of England.
- The cost will be £405 per person. (This applies to both the deafblind and their support workers, and covers accommodation, food and all the activities.)

The Calvert Trust is an "Adventure for All" centre and we will give the participants the opportunity to experience a British outdoor education tradition.

To see a short film of some of the English members of the Outdoor Network who visited the centre this year visit: https://youtu.be/_VYcxkNpmj4

For more information on the Calvert Trust visit:

<http://www.calverttrust.org.uk/exmoor/exmoor>

To register an interest please contact either: **Jon Fearn –**

Jon.Fearn@sense.org.uk or **Joe Gibson – jgibson@sensescotland.org.uk**

Research Network

Walter Wittich reports:

The first six months of the Dbl Research Network have been full of activity and discovery. As of November 2015, we now have 75 members on our e-mail contact list.

A big *Thank You* goes out to Saskia Damen and Flemming Ask Larsen for the creation and maintenance of the Deafblind International Research Network – Facebook Group (<https://www.facebook.com/groups/158743377516989>) currently at 84 members and growing. Also, another big *Thank You* to Christine Lehane, who has taken on the creation and maintenance of our Deafblind International Research Network LinkedIn group (<https://www.linkedin.com/grps/Deafblind-International-Research-Network-8339092>) currently with 5 conversation streams.

Susan Bruce has actively been promoting collaborative opportunities already, specifically by creating the Action Research Working Group, and you can learn more about her efforts on our Research Network web page

<http://research.deafblindinternational.org>.

We look forward to hearing from you. So please feel free to check out the networking opportunities on our web page and contact us with your interests and ideas.

Walter Wittich on behalf of the Dbl Research Network Team
(walter.wittich@umontreal.ca)

Usher Network

Emma Boswell reports:

The Dbl Usher Network has been busy producing a special piece of work at the moment, as well as publishing several articles from the Usher Network Pre-conference, held in Belfast in November 2014.

Several committee members, in particular Nadja Hoegner from Germany and Karen Wickham from Australia, have been putting a lot of time into pulling together a brand new resource about the Usher network which will be up and running as soon as the final tweaks have been made.

We are looking forward to sharing this informative online resource with you soon.

The new revamped webpage about Usher Network on the Dbl website (<http://usher.deafblindinternational.org>) will include information about Usher syndrome and material from other countries.

The content includes an informative Home page, What is Usher syndrome?, Current Research and Publications, Activities of the Network as well as forums and Members contacts.

We welcome you to join us online as soon as we release our refreshed and interactive section on the website.

Please come and have a look.

We are very pleased to welcome our newest committee member, Bettina Kastrup Pedersen from Denmark, welcome!

Emma Boswell (emma.boswell@sense.org.uk)
Co-chair of Dbl Usher Network

Youth Network

Simon Allison reports:

The Dbl Youth Network has held its very first youth exchange visit during October 2015.

A group of Deafblind youths from Sense in the UK travelled to Perth Western Australia to link up with youths from Senses Australia¹. Host families kindly accommodated the travelling group and transported the youths to a joint programme of activities.

Angela Wills from Senses Australia coordinated activities including a visit to Yanchep National Park², sailing on catamarans on the famous Swan River, a traditional Australian BBQ at Matilda Bay and barefoot bowling.

The group also represented Deafblind international during a visit to meet Kerry Sanderson, the Governor of Western Australia. A full tour of government House followed the meeting.

The exchange visit also included performances by the Sense young person's drama group GOT 2 ACT³. The group performed 3 plays including a piece about Helen Keller. The performances at Mosman Park Primary School and the Rendezvous Hotel created much media interest and were both featured on the Australian ABC News Network.

After a successful nine day visit many friendships were created. The UK youths are looking forward to a future visit from the Australian youths.

For more information about the Youth Network, contact Simon Allison, Youth Network Coordinator (simon.allison@sense.org.uk) and check out <http://dbiyn.deafblindinternational.org>

¹ www.senses.org.uk. Senses Australia is a large corporate member of Db!.

² www.dpaw.wa.gov.au

³ <https://www.sense.org.uk>

Social-Haptic Communication Network

Riitta Lahtinen and Russ Palmer report:

This year we have supported professionals to understand social-haptic communication in Brazil and Holland. In Brazil professionals and deafblind people were very keen to develop how social-haptic communication can be applied to everyday life situations. We were invited to share our expertise and research work on haptics and haptemes with them in several ways.

Earlier in 2015, we gave a presentation at a virtual conference (III Forum Virtual Ibero Latino Americano Sobre Surdocegueira e Deficiencia Multipla Sensorial). We

travelled to Brazil in July and presented a key note speech and workshops at the Federal University of Santa Maria¹ and in Sao Paulo at the University Estácio de Sá². This was followed up by giving a lecture via skype at the VIII National Meeting of Families and Professionals Specialized on Deafblindness in Sao Paulo Brazil, November 2015.

There was a lot of enthusiastic feedback from the participants. Professionals and families raised some interesting issues. Vula Maria Ikonomidis one of the organisers from AHIMSA/Grupo Brasil³ collated the feedback. Julieta de Fátima, an experienced teacher from the deafblind school (AHIMSA), realized how much touch she uses to confirm information given to her students. She remembered a student she sees in a home visit program due to his severe health condition. He is in bed all the time and his limbs are suffering atrophy from immobility but she noticed he can control and blink one eye and use one finger. He pays attention to whatever she presents visually and she is starting to use more touch to make sure he understands and the communication is not limited to his sight. She believes that by learning social haptics he can have more contact with his family.

Susana Araújo, a parent, made comments about how she communicates, through combined touch cues, with her completely deafblind daughter. When they are moving around she has some special touch cues on her arm to indicate whether there are stairs, or a place to sit for instance. In a conversation with Claudia Sofia and Carlos Jorge representing the Brazilian Deafblind Association Abrasc³ they also expressed how useful and adaptable haptics are with deafblind people, their guide interpreters, professionals and family members.

Just before leaving Brazil, Russ was admitted into a hospital for two weeks with a serious skin infection. He has made a short video in sharing his experiences from a deafblind view on how to adapt haptics with the nurses and other practical ideas. You can see this video on YouTube by typing “Russ Palmer hospital Brazil”⁴.

For further information about the Social-Haptic Communication Network, contact: riitta.lahtinen@kolumbus.fi or rpalmer2@tiscali.co.uk; www.russpalmer.com and <http://socialhaptic.deafblindinternational.org>

¹ www.ufsm.br

² www.estacio.br

³ www.ahimsa.org.br

⁴ www.asbrac.com.br

⁵ www.youtube.com/watch?v=xfEbNaszE7k

Using haptics in health care settings

Riitta Lahtinen, Ph.D, Russ Palmer, Music Therapist and Sanna Tuomaala, Youth Instructor

Haptics are touch messages which are produced onto various parts of person's body which resemble words or signs. Haptics have their own grammar, and they form their own linguistic system, the social-haptic language. Haptics are formed in

different ways; some are a natural description of an activity, while others are based on writing, signing or visual symbols.

When signs are changed into haptices, their grammatical structures change. The skin, the sense of touch and the kinaesthetic sense¹ (or movement sense) form a distinct channel for receiving messages as compared to the eye or the ear. Haptices are comprised of haptemes (compare phonemes, and the grammar of signing). Haptemes are for example pressure, duration, direction and speed (Lahtinen 2008). The social-haptic language is composed of haptemes. During social-haptic communication two or more people produce/receive touch messages whereas in haptic communication information is received from a technical device by using touch (e.g. haptic feedback). The intentional development of haptices began in the 1990s. The first lecture on the topic was presented in 1993 at the 7th Usher Study Group² meeting in Potsdam, Germany (Lahtinen & Palmer 1993). Haptices can be grouped into several sub groups. One type are those used in a particular situation or by a specific group of professionals. This article illustrates haptices used in hospitals by health care professionals. As developers of haptices Sanna and Russ tell of their own experiences.

Sanna Tuomaala reports about her experience with haptices in a recovery ward

I have Usher syndrome³. With the progression of this condition, my hearing and vision will both deteriorate. Presently, I use two cochlear implants (CI)⁴ with which I can hear fairly well in quiet surroundings. My vision is very narrow, only about 10 degrees. I become deprived of sight temporarily due to bright lighting conditions. Mobility in unfamiliar places is difficult without a guide. I communicate in speech, sign language and also in tactile signing, if necessary. In addition to these, I use social-haptic communication.

The hospital is one place where haptices are useful. Imagine a patient, who hears and sees barely anything as the result of medication, a hearing and vision disability, or some other reason. In such a situation, touch is an excellent channel for receiving information; for example, what is happening in the room or what will be done next. I participated (with others) in developing haptices and testing haptices in a hospital situation. The nurses informed me of the most important incidents and actions to be taken by using these touch messages onto different parts of my body. The following haptices were tested in authentic hospital setting when I had my first CI-surgery: doctor, don't worry, vaccination, blood pressure, it will hurt now, the time and "Is everything fine?" In that situation, the touch from another person gave also a sense of security and felt reassuring.

Russ Palmer reports about his experiences with haptices in several medical situations

I also have Usher syndrome. I use two cochlear implants, with which I get along in peaceful surroundings. I am also blind and when out of my home, I always need a guide. I communicate using speech, English finger spelling and social-haptic communication.

I have been developing haptices, teaching their use and analysing their grammar (i.e. haptemes) since the beginning of the 1990s. I use haptices all the time in various kinds of situations both with family members as well as with interpreters and personal assistants. For me, social-haptic communication is a natural, linguistic means of communication.

When I face a new situation, for example my cataract surgery, I tried to consider in advance what is a safe way of getting situational information. I knew that during the cataract surgery I could not use my cochlear implants. In that situation I am deafblind. Riitta and I used haptices that we had agreed beforehand (see photos) which worked well.

I have used those haptices also in other hospital and health care situations. Recently, for example, haptices were very useful while in the hospital in Brazil (Palmer, 2015) where only Portuguese was spoken by the hospital personnel. It was quicker for the nurses to learn to use haptices than to learn to pronounce English words. Haptices can be used together with cochlear implants or without them. Pictures of the most common hospital haptices are shown. Deafblind persons may use this list of haptices and take them along in health care situations and introduce them to the health care personnel. Haptices are easy to learn because they are based on the activity and provide logical messages regarding the medical procedures to be done.

For further information about haptices, contact: riitta.lahtinen@icloud.com and www.russpalmer.com

Haptices in a hospital

Practical haptices for a person who is deafblind or hard of hearing. Haptices will help with communication in a hospital and for deafblind individuals also with orientation in a situation when other devices are not in use.

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Russ Palmer hospital Brazil link (2015):
<https://www.youtube.com/watch?v=xfEbNaszE7k>

¹ medical-dictionary.thefreedictionary.com/kinesthetic+sense

² Usher study group is now called the Dbl Usher Network (<http://usher.deafblindinternational.org>)

³ www.nidcd.nih.gov

⁴ www.nidcd.nih.gov

Research

Action research in deafblindness series

Dr. Susan Bruce

This is the first in a series of articles about action research written by members of the Action Research Work Group of the Deafblind International (DbI) Research Network. The purpose of this series is to provide information to support practitioners to conduct research. Systematic research by practitioners holds the promise of expanding our knowledge of effective practices in deafblindness. This paper begins the series by defining action research and describing types of action research. Future articles will describe how to conduct action research studies and share descriptions of studies in deafblindness.

Article #1: Defining and Describing Action Research

What is action research?

Action research is a problem solving form of systematic inquiry. It starts with the identification of a problem of interest to a practitioner. This problem is then translated into a researchable question. Through reflection about the research question, the practitioner determines the potential actions that might be taken and how those actions could be measured. One of the hallmarks of action research is that it involves cycles of action and reflection (Pine, 2010). So, unlike most types of research, the intervention or action is not static. The practitioner reflects, develops an intervention (the action), measures its impact, and then reflects about what has occurred. The practitioner, informed by data, then determines to continue with the intervention or to make changes (e.g. implement a new action) that might be more effective. Thus, action research may involve one cycle of action and reflection, but it is far more likely to include multiple cycles of action and reflection. The recursive problem-solving nature of action research makes it particularly suitable to complex challenges that occur in complex settings that experience change.

What are the types of action research?

Hendricks (2009) described four types of action research: classroom, collaborative, critical and participatory. Classroom action research focuses on an issue of importance in the classroom that may involve a single student or multiple students. For example, classroom action research might focus on how to support all students to increase their interactions with each other or it might focus on the communication development of one student. Classroom research, sometimes called teacher or

practitioner research, should build on the abilities of students, rather than focusing on deficits (Wansart, 1995). Thus, intervention builds on what the practitioner knows the child or youth can do. Although Hendrick's schema discusses classroom research, the same ideas may be applied to research in non-school settings including those that serve adults who are deafblind.

Collaborative research occurs when the practitioner involves others outside the immediate classroom or community setting. This may include colleagues, university collaborators, or others who bring either knowledge of the issue (such as an expert on communication) or of the research process (Hobson, 2001). The success of such collaborative relationships is dependent on voluntary participation, delineation of roles and responsibilities, clear communication, and established timelines for the work (Stevens, Slaton, & Bunney, 1992).

Critical action research has a strong social justice component. It addresses issues of inequity rooted in prejudice and discrimination. Critical action research studies examine how social and political forces cause inequity (Bruce, 2010). Collaboration is also a characteristic of critical action research, but the collaborators are from outside the classroom or other setting. They are often members of the community who have personal experience with the issue being examined. In studies about issues faced by individuals who are deafblind, children or adults who are deafblind, their family members, close friends, and service providers could be included.

Participatory action research (PAR) in special education or disability studies includes individuals with disabilities as co-researchers. The distinguishing feature of participatory research is that the participants (in this case, individuals who are deafblind) identify a problem or issue of concern to them that is then shaped into the research question(s). In PAR, the individuals with disabilities assume co-researcher roles of their choosing, such as participation in data collection, data analysis, and dissemination in various forms (Balcazar, Keys, Kaplan, & Suarez-Balcazar, 1998). Self-determination and advocacy are central tenets of participatory action research studies (Porter & Lacey, 2005). Emancipatory action research is considered by some to be a form of participatory action research. In emancipatory research power is held by the individuals with disabilities and the goal is to make social change to improve the quality of life.

For more information, contact Dr. Susan Bruce, Professor, Boston College
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Psychosocial aspects in Usher syndrome

Nadja Högner

Introduction

Usher syndrome (USH) is a genetically recessive based condition causing both sensorineural hearing loss and progressive vision loss caused by retinitis pigmentosa (RP), an eye condition affecting the retina. RP leads to symptoms such as night blindness, reduced visual acuity, and concentric visual field reduction (tunnel vision). USH can lead to blindness, but need not. Depending on the degree of hearing impairment, the syndrome is ascribed three clinical types: USH1 is characterized by congenital deafness and balance problems; individuals with USH2, the most frequent type worldwide, experience moderate to severe hearing loss from birth with normal balance, while individuals with USH3 have a progressive hearing loss with normal to near-normal balance (Kimberling & Möller, 1995). Within these three clinical types there are many genetic types, which lead to a huge variability in USH.

Currently, the main focus of USH research is on the medical and genetics aspects of the syndrome. Studies that focus on life management and psychological well-being, while being more significant to individuals with USH, are comparably very rare. This

article provides an overview of the recent international research studies focussed on the psychosocial situation of people with USH.

In this article I will address the issues related to the psychosocial situation of people with USH through the aspects related to diagnosis, stress in different areas of life, mental health issues, social stress, self image and self esteem, sense of humor and coping strategies and programs.

1. Diagnosis

“I went to the doctor and he told me that I would go deaf and blind. He does not know when, but it might be in the near future. Then the doctor abruptly left the room. No! Not my hearing, not my vision! It is not fair! How could God do this to me? Why wasn't I told until I was grown up? Somebody help me!!!” (Möller, 2007, p. 59).

This quotation shows that the diagnosis of USH can be associated with such reactions as shock, devastation, confusion, despair, denial, grief, guilt, helplessness, depression and anxiety. These are results of a survey from Ilene Miner who asked 39 people with USH and their family members about their diagnosis (Miner, 2014). The respondents told Miner that the information given by the medical doctors was often too medical and therefore incomprehensible. They often lacked specific information and individual prognosis; for instance, medical doctors told one person that she might go blind, based on general assumptions. Respondents also indicated that they were given too little time to discuss issues regarding USH.

Another problem that was reported was how late the diagnosis were given. In an earlier study, Miner reported the mean age of USH diagnosis was 18 years (Miner, 1997). However, Högner (2014) reported that the mean age of identification in a German sample was 32 years.

2. Stress in different areas of life

Figueiredo, Chiari and Goulart (2013) conducted interviews about different types of stress reported by 11 people with USH (aged 20–57 years) in São Paulo, Brazil. Six of those individuals reported a negative affect on their daily activities, six experienced difficulty at work; two in leisure activities. Four of the individuals reported a change in their family situation due to USH.

Ellis and Hodges (2013) analysed stress in various aspects of life through interviews with 44 people aged 14 to 56 years with USH in the UK (17 USH1, 22 USH2 and 5 USH3). The respondents reported problems in the areas of communication, mobility, family/friends/support networks, education, work and leisure. In all of these areas USH has two sides: frustrations and challenges with accepting USH such as learning to ask for help and finding a job. However, it depends on the attitude of the person with USH to perceive whether an issue is challenging or frustrating. Since USH is highly associated with unpredictability of timing and the extent of changes, people with USH are often stressed by aspects related to not knowing whether they will go blind; or if they do, when will it happen; when will they need to give up driving, working, use a cane etc.

Högner (2014, 2015a, 2015b) developed a questionnaire in her doctoral thesis to assess stress frequency and intensity in 262 people, aged 17 to 79 years, with

USH2 in Germany. When the mean values of the frequency and intensity of the various stress determinants were placed in a descending order, the distribution of the results for frequency and intensity were similar. The highest stress was in the area of orientation and mobility, followed in descending order: recreation, auditory communication, daily life skills, social interactions and employment. Thus, orientation and mobility is a serious problem area since their vision loss cannot be compensated with the auditory sense.

3. Mental health

Wahlqvist, Möller, C., Möller, K. and Danermark (2013) carried out a comparative study of the physical and psychological health of 96 people with USH2 in Sweden, (aged 18 to 84 years) with 5,738 non-USH individuals from the main Swedish population. The USH2 sample of individuals reported more fatigue, more problems with concentration and being able to complete tasks, more feelings of worthlessness, being constantly under strain, unhappy and depressed. They reported experiencing more anxiety and worry; more thoughts and actual attempts at suicide.

In a follow-up study, Wahlqvist (2014, unpublished) examined the physical and psychological health of persons with USH1 and USH3. Preliminary results presented in a lecture in Potsdam Germany (2014) indicated that among individuals with USH1, their psychological problems included headaches, fatigue, loss of confidence, strain, feelings of worthlessness, suicide behavior, lack of social trust, and social isolation. For those with USH3, common issues reported were fatigue, sleeping problems, stress and worry, suicide thoughts and attempts, social withdrawal and a general mistrust of others.

4. Social stress

The author (Högner, 2014, 2015a, 2015b) used the Trierer Inventory of Chronic Stress (TICS)¹ to measure the frequency of various kinds of stress experienced by 262 people with USH2 (aged 17 to 79 years) compared to 604 non-USH individuals within the main German population. The stress experiences were divided into two broad areas: aspects of social stress and aspects of work stress. The social stress scales examined were: Social Overload, Lack of Social Recognition, Social Tensions, Social Isolation and Chronic Worry. The results from the USH2 sample regarding social stress indicated that the individuals experienced a higher level of stress in the scales: Social Tensions, Social Isolation and Chronic Worry. The highest stress reported by the USH sample was Chronic Worry, an indication that USH is associated with internal stressors. The individuals reported less stress in aspects of Social Overload due to their being involved with fewer social commitments due the restrictions of USH.

Stress scales studied associated with work included: Work Overload, Success Pressure, Discontentment with Work. The results regarding the work stress in this study will be shown in a future article.

5. Self image and self esteem

In the study from Ellis and Hodges (2013) the standardized Self Image Profile (SIP)² was used for 30 USH-adults aged 19 to 56 years (9 USH1, 17 USH2, 4 USH3) and 11 USH-children aged 14 to 18 years (6 USH1, 4 USH2, 1 USH3). Both groups were compared with the main population (1,303 non-USH adults and 892 non-USH children). No differences were found between the two groups. The authors compared the scores, which are in normal ranges, but no statistical tests were used. Regarding self image and self esteem, adults saw themselves (in descending order) mostly as honest, trustworthy, friendly, loyal, and caring, and at least thin/slim, optimistic, fit, patient, and confident. Children saw themselves as being mostly friendly, helpful, funny (and fun to be with), but also tending to worry a lot, an indication of psychological problems. Children were least likely to view themselves as bossy, sarcastic/bitchy, annoying, messing around and moody (Ellis & Hodges, 2013).

6. Sense of humor

The author (Högner, unpublished 2014) carried out a study about the use of humor to cope with stress using the Coping Humor Scale³ (CHS) and about the sense of humor using the Sense of Humor Scale⁴ (SHS). The study involved 86 persons aged 27 to 75 with USH (2 USH1, 83 USH2, 1 USH3). The USH sample was compared with the main population (CHS n = 110, SHS n = 151). The results with the CHS indicated that people with USH used less humor to cope with stress. According to the sense of humor scale, people with USH laughed less, were less playful (and in a positive mood) and used less humor under stress. The results can be explained in numerous ways: the inability of individuals with dual sensory impairment to perceive humor in the face of others and hear them laugh; combined with their individual stress, their social isolation, fear and worry and depression.

7. Coping strategies and coping programs

In the study from Ellis and Hodges (2013), people with USH were asked about their coping strategies. The respondents told them that they are “doing things while they still could” (p. 8, 218). This means that some individuals hold onto activities as long as possible (e.g., by continuing to drive their car), while others are trying to cope with the changes as soon as possible by finding alternatives (e.g., changing to cycling tandem), through adaptation and modification (e.g., lighting and change to work from full to part-time), learning new strategies (request for help), using aids (such as the long cane, cochlear implant, Smartphone) and making contact with other USH people (e. g., in self-help groups and virtual networks such as Facebook). In a study by the author (Högner, 2012), 17 USH individuals (23 to 58 years) were asked in interviews about their individual coping strategies. They indicated such activities as sports, dancing, walking, social relationships with significant others, exchange with other USH people (in self-help groups and volunteer work), the conscious creation of recovery times and relaxation exercises (e.g., yoga) and the use of humor.

Côté, Dubé, St-Onge and Beaugard (2013) developed a group intervention program for 7 USH2 individuals (aged 42 to 63 years) focused on managing

personal goals. The goal was to support the adaptation process in USH through setting, planning, and pursuing a goal and learning strategies to achieve these goals according to the following steps: 1) goal setting (identification and evaluation of personal desires and objectives, negative thoughts, and choosing a priority goal); 2) goal planning (choosing methods and strategies to overcome obstacles), and 3) goal pursuit (concrete actions and adjustments). The program has led to increased values in the variables “meaning of life” (significant), feeling of “serenity”, “self-determination”, and the “ability to set, plan, and pursue a goal”. The authors suggest that to produce a significant improvement in all areas, a more sustained rehabilitation program is needed.

Implications and recommendations

To establish early rehabilitation measures for individuals with USH, an early diagnosis is needed. In view of such genetic treatments as next generation genome sequencing⁵, an early diagnosis could be provided with relatively few costs.

The results of the studies show clearly that psychological problems have to be more focused in research studies. This means that in individuals with USH, the psychological problems should be addressed, assessed and treated.

It is important to make aware the psychological stress and problems occurring in the lives of individuals with USH. Their mental issues could be assessed using standard questionnaires or inventories.

Psychotherapy could be suggested to help individuals with USH to reduce their fears and worries; suggest ways for them to overcome their social isolation and depression. However, it is more important for these individuals to have contact with experts who understand USH and its consequences. For instance, understanding the personal losses due to USH (e.g., driving, employment, independence etc.) and the fear or worry related to these losses, such as going blind (Miner, 1997).

According to Miner (2014) these personal factors are more urgent and important for the individual than knowing the medical details about USH. Furthermore, this type of intervention should be considered together with attempts to find humour in everyday situations and learning how to use humor as a coping strategy. To succeed this requires interdisciplinary cooperation among medical specialists, psychologists and pedagogics. “USH is about loss, change, adaptation, information, communication, normalization, and fighting against the isolation” (Miner, 2014). Our professional roles, according to Miner, are to mitigate the impact on those we teach, treat, are friends with and love.

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¹ www.emf-portal.de/gl_detail.php?l=e&id=3566

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³ psycentre.apps01.yorku.ca/drpl/commercial-test/coping-humor-scale-chs

⁴ www.ncbi.nlm.nih.gov/pubmed/10063247

⁵ The catch-all term used to describe a number of different modern sequencing technologies.

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Physiological Self-Regulation in CHARGE Syndrome

Andrea E. Larsen¹, Timothy S. Hartshorne², David Brown³, and Jude Nicholas⁴

“Once in graduate school when I was studying at my favorite study carrel in the library, someone sitting right behind me started tapping the desk with his pencil. It slowly drove me crazy. The noise completely distracted me, I began to squirm in my chair, I started to sweat, and my stress levels increased dramatically. I lost the ability to keep myself in a nice, calm state. Several interventions posed themselves, one was rather violent; but, the most reasonable was to move to a different carrel.” (Tim Hartshorne)

Consider the experience of walking into your living room at home. Is your attention drawn to the paintings on the wall? Or to the peculiar way the furniture is arranged? Most likely you do not even notice. These perceptions are habitual for you. They have faded into the background. But imagine instead walking into the room to show a friend who has never seen it before. Now you notice the discoloration on the wall, and the messy way papers and magazines are piled on the coffee table. Your perceptions have become much more sensitive to the environment.

Humans generally learn how to habituate to their experience, both internal and external. Habituation is the process by which an individual decreases or ceases to respond to an initially novel stimulus after repeated presentations. In other words, we stop noticing that crack in the ceiling because it has become so familiar. Thus, habituation is characterized as the filtering out of sensory impressions which are no longer relevant. If we could not do that, we would end up being highly over-reactive, as with the tapping of the pencil. At other times it is beneficial to be highly sensitive to what is going on around us so that we do not miss noticing things that could be very important.

Physiological self-regulation refers to the ability to alter internal states and functions to maintain or regain a state of homeostasis in response to demands on the individual (Sedges, 2007). It is important to be able to regulate homeostasis, like a thermostat. Self-regulation involves the ability to efficiently adapt to and alter one's response to over and under stimulation. Physiological regulation describes the way the individual reacts, or their reactivity, to stimulation, which is under the control of the somatic, endocrine and autonomic nervous systems. However, it is also capable of conscious and deliberate management. Self-regulation attempts to manage this reactivity in a manner that allows the individual to still pursue goals. If you need to study, and your arousal level is too high (over reacting) where you are sitting, you might try moving to a less distracting spot.

Dunn (1997) describes how self-regulation can modify the degree of arousal (or reactivity) that we experience. In this model, we may be in a state where we are easily able to ignore much of the external stimulation in our environment, and maintain a low arousal level. We have habituated to the distracting stimulation in the environment (you tune out the pencil tapping). Or we may be in a state of high alert and notice everything going on around us. We are in a state of sensitization (the tapping seems to become more pronounced). Self-regulation can support habituation, or under arousal, by simply not reacting to or tuning out any stimulation (simply tune out the pencil tapping), or it can support sensitization, or over arousal, by deliberately noticing and reacting to stimulation (react strongly to the tapping). On the other hand self-regulation can actively work against the level of arousal by focusing full attention on all aspects of the situation when under aroused (sensation seeking), or by withdrawal of attention away from stimulation when over aroused (sensation avoiding). The pencil tapping situation involved a highly sensitized state, and the initial response was reacting to the stimulus. Moving to a different, quieter, carrel, would have been the more active self-regulatory strategy of sensation avoiding.

An individual's capability to efficiently self-regulate rests upon several factors related to the maturation of psychological and physiological functioning (Marcovitch, Calkins, Leerks, O'Brien, & Blankson, 2010). Although limited, infants display regulatory processes from birth, and these become more sophisticated as they develop. Most of the stimulation that infants must first learn to react to is through sensory input. They see, hear, smell, taste, and touch, and they learn to balance (vestibular sense) and they figure out where their body parts are and how they are attached (proprioceptive sense). Using each of these senses they gradually learn to habituate or react as needed for the task in front of them; for example, they can tune a noise in or out depending on their goals at the moment. The responses produced as they self-regulate are generally found to be fairly stable amongst infants, but the sensory threshold level required to generate a response may vary (Calkins & Fox, 2002). Physiological self-regulation requires the active management of these thresholds of habituation and reactivity to allow optimal performance in the pursuit of a goal. Capabilities to self-regulate physiological states become increasingly more controlled as one develops. In children, gains in self-regulation have been found to correlate with increased ability to attend and motor control (Calkins & Fox, 2002).

The proper functioning of many internal and external responses is dependent on the maintenance of a physiological balance referred to as homeostasis. Numerous physical and chemical variables, such as one's body temperature, are constantly maintained within a set range. Maintaining a homeostatic balance is crucial for the effective functioning and survival of all cells. Preserving one's internal environment can further influence one's reactivity, and the ability to uphold a desired level of awareness (Bornstein & Suess, 2000).

There are several physiological measures of how well the individual self-regulates. Resting heartbeat (Groome, Loizou, Holland, Smith, & Hoff, 1999), brain electrical activity (Compton, Hofheimer, & Kazinka, 2013), and levels of the hormone cortisol (Calkins & Fox, 2002) have all been used to better understand self-regulatory strength. Researchers have also been interested in how self-regulating can wear a person out, making it harder to self-regulate the next time. If you use your self-regulatory strength to tune out pencil tapping, you may have a harder time later that same day when you have to regulate another event. It appears blood glucose levels are affected. Reductions in self-regulatory strength due to declining glucose levels can be generally reversed through glucose consumption (Galliot, Baumeister, DeWall, Maner, Plant, Tice, & Brewer, 2007).

Physiological Self-Regulation in CHARGE

Individuals with CHARGE syndrome are truly multi-sensory impaired (Davenport & Hefner, 2011). The initial development of self-regulation in infants is largely dependent upon sensory stimuli. Therefore, a child born with CHARGE is immediately placed at a disadvantage for the development of self-regulatory mechanisms. Problems with being able to completely experience the sensory world can impact the understanding of the environment, reduce the benefit of modeling, and increase the level of confusion and uncertainty. Children with CHARGE will still make self-regulatory adaptations, but these can take a long time to create. For example, the boy pictured here is watching television. This is normal viewing posture when you have no vestibular sense, upper visual field loss, poor tactile and proprioceptive perception, and low muscle tone. This boy has figured out a way to regulate his attention by stabilizing and thus regulating himself. Hanging upside down by children with CHARGE is frequently reported by parents. It can be a way to regulate the physiological state of the individual so that goals may be achieved. Difficulty with balance is common in CHARGE. Brown (2005) identifies challenges such as memory deficits, managing sensory perception, and utilizing body language. Also impacted are postural control, equilibrium, muscle tone, and motor coordination. Low muscle tone has been related to diminished levels of sensory input and perceptual awareness. Balance difficulties pose delays in the maintenance of a stable visual field and may contribute to attentional and motor development deficits. The possible impact on self-regulation is not known, although research has found that increased attentional capacities and motor control signify advanced self-regulation in infants (Calkins & Fox, 2002). Vestibular problems would most likely make certain kinds of physiological self-regulation more challenging because the

person must deal with and attend to their unsteadiness, in addition to whatever else might be confronting them.

Children with CHARGE typically display a variety of anomalies that interfere with proper neurodevelopment (Gilles, 2011). Multiple cranial nerve anomalies appear to be common. These nerve dysfunctions may be related to absent or reduced sense of smell, breathing difficulties, and problematic issues pertaining to swallowing. Dysfunction of the nerves within the face may result in facial palsy and a significantly reduced ability to taste. The impact of neurological differences have yet to be studied; however, they would likely impact the child's ability to self-regulate. Executive functions, presumed to emanate from the prefrontal cortex, are those capacities used to organize oneself in the environment so that the individual can sustain attention to tasks, shift attention, inhibit behaviors, and initiate actions. There is evidence linking executive functions with the physiological response and regulation of stress (Williams, Suchy, & Rau, 2009). For instance, cardiac activity (i.e. heart rate), a measure of stress reactivity, is controlled, in part, by the prefrontal cortex, the same brain region housing many of the cognitive processes encompassed by executive functions (Lin, Heffner, Mapstone, Chen, & Porsteisson, 2014). Thus impaired executive functions are likely to have a direct effect on the regulation of stress response systems. Hartshorne, Nicholas, Grialou, and Russ (2007) used the *Behavior Rating Inventory of Executive Function* (BRIEF) to study executive functioning in children with CHARGE. High scores were found for shifting attention, the ability to self-monitor one's actions, and inhibiting behavior. The BRIEF has a "behavioral regulation index" on which over half the children received clinical scores.

Self-regulation can also be impeded by pain (Sauer, Burris & Carlson, 2010) and stress (Blair and Diamond, 2008). Children with CHARGE syndrome are at risk for experiencing much higher levels of physical pain and psychological stress throughout their lives (Nicholas, 2011; Stratton & Hartshorne, 2011). Both internal and external stressors such as the presence of emotional stress and physical pain initiate the body's physiological stress response in the attempt to restore homeostasis. Individuals with CHARGE appear likely to experience many threats to their homeostatic balance, and the resulting stress can impede the maintenance of physical, cognitive, and emotional difficulties, and hinder self-regulatory capacities (Sauer et al., 2010).

Possible Interventions

Sensory Stimulation

The first means of developing self-regulatory skills during infancy is typically dependent upon one's senses. Promoting sensory stimulation may be beneficial for the self-regulatory capacity in children with CHARGE, due to extensive multi-sensory impairments. However, each child diagnosed with CHARGE possesses their own unique sensory needs. Occupational therapists can create "sensory diets" specifically tailored towards each individual. A "sensory diet" refers to a list of recommended activities and modifications based on the child's daily sensory needs, such as the use of a trampoline, a sandbox, simple exercises, finger-fidgeting, and

applying a weighted vest or blanket (Nackley, 2001). Before a suitable “sensory diet” can be generated, the child should be assessed for deficits in motor control and proprioceptive, vestibular, and tactile information processing.

Mindfulness exercise

Interest in mindfulness interventions has been growing for a number of years (Brown, Ryan, & Creswell, 2007). The key to self-regulation in this context is the directed attention of the person to their subjective internal, emotional and physical experience (Brown, et al, 2007). Yoga is one mindfulness exercise that has been used with children who are deafblind (Karnad, 2002). Barrey-Grassick (2011) adapted Tai Chi for children who are deafblind and those with CHARGE. These practices have the potential to develop self-regulation skills.

Wilbarger Protocol

A unique treatment plan known as the Wilbarger protocol, also referred to as brushing and joint compression, was specifically designed to meet the needs of children who experience deficits in sensory reception and integration. It is intended to help children achieve and sustain optimal levels of arousal (Kimball, Lynch, Stewart, Williams, Thomas, & Atwood, 2007). Application of the protocol not only entails sensory stimulation, but promotes relaxation which can further aid in the reduction of stress (Kimball et al, 2007).

Employing the technique involves a specialized non-scratch brush which is used to apply deep pressure. Following the pressure, each of the major joints must then be compressed. This procedure must be used only after proper training, and followed on a routine basis for optimal benefit (Kimball, et al 2007).

Diet

The ability to utilize self-regulation is affected by blood glucose levels, and so a balanced diet and adequate fluid intake is important. It is beneficial to eat several smaller meals throughout the day and focus on including a sufficient amount of carbohydrates into the diet. Foods lower on the glycemic index are preferred because they prolong the release of glucose, which aids in reducing fatigue (Hagger, Wood, Stiff & Chatzisarantis, 2010).

Case Example

The student was an eight year old boy, profoundly deaf, blind in one eye with reduced visual field in the other eye, late independent walking (aged 4), and with continuing feeding issues. He attended a program for the deaf. The boy had impressive receptive and expressive language in American Sign Language, but showed characteristic difficulties with initiating utterances. Problem behaviors’ were distractibility, impulsivity, and physical aggression against others. During two days of observation it was apparent that episodes of high arousal leading to violent outbursts were related primarily to periods of enforced sitting for up to 25 minutes at a time. Recommendations included providing a high desk so that the boy could stand to do his schoolwork – he enjoyed this and showed greatly improved attention

span during lessons with fewer aggressive outbursts, swaying his body from side to side and stepping from one foot to the other as he worked. Significantly improved attention was also observed after the weekly 30-minute adaptive physical exercise session, so as a result these sessions were increased to three times a week, and physical activities providing more and stronger proprioceptive and vestibular input were added – mainly swinging by the arms from an overhead beam, trampolining, wheelbarrow walking (student walks on their hands and arms with their legs held up by an adult), and pushing the heavy equipment cart a long distance to and from the exercise room. The student had received an occupational therapy brushing and joint compression program as an infant, and the recommendation that this kind of program should be offered again was taken up by the school, who reported that the student enjoyed the session twice a day and appeared to benefit from it in terms of improved self-regulation with better attention span. A more general recommendation was for classroom staff to wait for the student's visual attention before communicating to him, to sign a little more slowly, and to generally reduce the pace at which activities were carried out. All these suggestions were facilitated by the fact that the student already had an allocated one-on-one classroom aide – originally purely to impose physical control on the student, but increasingly fulfilling the functions of a deafblind intervenor as the benefits of these recommended changes became apparent.

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A research strategy to explore the impact of deafblindness across the lifespan¹

Dr. Anna McGee

Background

In July 2010 Sense² decided to establish a team to design and implement a series of research projects exploring the impact of deafblindness upon individuals across the lifespan. The underlying principle of this initiative was that deafblind people develop through the relationships that they have with their families, their peer groups

and the organisations who provide services for them so it would be valuable to understand how interactions with these groups of people could be facilitated. A small team was recruited to complete externally funded projects, to establish new projects to be funded by Sense that would be undertaken by university teams, and to support service based staff to undertake projects in the context of their usual work duties. Each member of the team had a different area of expertise so that all aspects of congenital and acquired deafblindness could be addressed. They included a developmental psychologist, a vision scientist, a sociologist with expertise related to older people and one research officer was herself deafblind as the outcome of Congenital Rubella Syndrome (CRS). The team also had access to a technology officer who is an audiologist, so the range of skills would support a wide range of research activity.

Research Projects

Two projects had already been funded from external sources before the research team was established. The Rubella Immunisation Project³ (funded by the UK Dept. of Health) evaluated perspectives amongst ethnic minority groups of the MMR immunization. The results indicated that groups of people who had decided to settle in the UK from a wide range of countries all intended to take up the opportunity to immunize their children, regardless of whether there had been a similar programme in place in their country of origin, although they did find the schedule of immunization complicated.

A project to explore awareness of Dual Sensory Impairment in Elderly People living in Care Homes, funded by BUPA⁴, adapted a screening tool that had originally been developed at the Skadelen Centre in Oslo Norway. Of 100 residents, 15 were found to have dual sensory loss that had not been identified. Sense then developed a training programme to increase the awareness of care home staff to the need to identify dual sensory difficulties in this group of people using the screening tool. Whilst these projects were being completed, a series of meetings with academic research teams identified five new projects that focused on issues of dual sensory impairment across the lifespan. The aim of these projects was to alert the UK research community to the impact of dual sensory impairment across the lifespan so the initial projects stretched from infancy to old age in order to create a map to represent the life experiences of deafblind people. The primary intention was to support individuals themselves, along with their families, to identify how they could achieve their potential.

The new projects included:

- A project that explored parent/child joint attention in the tactile modality which aimed to identify interaction strategies that would support parents in establishing the optimal communication relationship to consolidate and extend the social development that underpins language and cognition.
- The Sense Assessment Toolkit for Multi-Sensory Impaired (MSI) Children was intended to collate a model for the techniques and approaches used by the Sense Children's Services team and to provide an evidence base for the value of the

Sense Assessment in identifying the optimal learning environment for deafblind children in their early years of education.

- An Evaluation of the Impact of Usher Syndrome on Life Planning explored how the self-identity of people with Usher Syndrome was altered following their diagnosis and mapped the impact that this had upon their life plans.
- A project assessing Elderly People with Acquired Dual Sensory Impairment (DSI) living in the Community examined the lives of a similar group of people to those who had participated in the BUPA Care Homes project but who had continued to live in their own homes. This project explored individual's decision making process in relation to seeking residential care and evaluated the relative significance of dual sensory impairment in the context of conditions associated with ageing such as dementia and physical frailty. The outcomes were intended to inform local service providers of the support needs of people with dual sensory impairment who chose to remain living independently.
- The potential use of Social Haptics⁵ by service based staff to extend the range of communication techniques for deafblind people was the fifth project to be undertaken as part of the first group of research projects

The second research strategy (2013) adopted a slightly different approach to identifying projects in that a number of teams *within* Sense were asked to identify issues they thought warranted further exploration. This led to a further five projects being designed to address these issues and extend the findings of the first set of projects. The new projects included:

- A project to evaluate possible diagnostic confusion between deafblindness and autism
- The Rare Syndromes Clinic project which explored the experiences of people when attending specialist hospital clinics as a result of genetic conditions that result in dual sensory impairment
- The role of technology in supporting elderly people with DSI to stay in their own homes
- The financial outcomes for deafblind people who are being transferred from one benefit (Disability living Allowance or DLA) to a new benefit (Personal Independence Program or PIP)
- How to assess the optimal school setting for MSI children

Two other streams of research activity occurred in parallel with the external projects established in the second research strategy:

Firstly, some smaller scale projects were undertaken by individual members of the research team. These included:

The Long Term Health Implications of CRS project which showed that there was an increased rate of epilepsy, diabetes and coronary heart disease in this group of people.

A project to assess the use of Monitoring Technology in Sense Residential Services that highlighted the need for training for staff to understand the potential benefits of such technology.

The Social Prescribing Project evaluated the impact on wellbeing of a group of socially isolated elderly people with dual sensory impairment being offered the opportunity to engage in community based craft project.

The Usher Information Survey asked people who were in contact with Sense to identify their information needs and advise how the organization could streamline its services for this group of people.

The Communicator Guide Project explored the hopes and expectations of people with dual sensory impairment at the point they seek the services of a communicator guide and then explored their perspectives after the implementation of the service to assess the impact of having access to such support.

The second type of activity was specifically devised to recognise the extensive experience of people who deliver direct services to deafblind people within Sense. Their insights represent a significant contribution to evidence based practice across the organization so a range of projects were undertaken by small groups of staff under the supervision of members of the research team. These projects included:

- Use of Video as a Training Tool for Sense staff
- Communication Concepts
- Impact of Bereavement on Sense staff
- Living Full and Active Lives
- Reduction of Medication in Sense Residential Services
- Facilitating friendships between Deafblind people
- Use of Personal Symbols
- Use of Sensory Rooms
- Inclusion of Deafblind people in staff recruitment
- Safeguarding people with little or no formal communication

Most of these projects are now completed and some have been presented at national and international conferences. The results of the scheme were intended to inform both service delivery and training within the organization.

Outcomes

The wider outcome of Sense's initiative in establishing a research function has been the creation of a *UK network* of academics who will now submit grants to external funding bodies to support research related to dual sensory impairment. This demonstrates that Sense has acted as a mechanism for influencing research that represents the perspectives of deafblind people within the UK. Members of UK based networks of other charities have also become more aware of issues related to dual sensory loss and this has led to collaborative projects *between* organisations that take a person-centred perspective, as participants are no longer viewed in the light of only one of their areas of difficulty.

Some of the Sense projects have also been replicated and extended by teams of researchers from settings *outside* the UK which indicates that there is an emerging *international network* of researchers who are now exploring collaborative opportunities through the new Dbl Research Network.

Within Sense the practitioners who undertook the practice based projects have increased their understanding of the value and significance of research and it is hoped that this will in time lead establishing a more robust evidence base for the value of the direct services that Sense offers.

One unexpected outcome of the dissemination of Sense's research activity at academic conferences has been the involvement of 2 MSc students and one PhD student who are now undertaking post-graduate research related to dual sensory impairment. As these individuals will become the next generation of academics, supporting them at this early stage in their careers is viewed as an investment by Sense in the future availability of researchers who are aware of dual sensory impairment.

What comes next?

Three of the projects established in the 2013 strategy are completing by the end of 2015 so these findings will add to the growing pool of evidence of the impact of dual sensory impairment across the lifespan.

A new proposal for a project that builds upon the outcomes of the Late Life Acquired Dual Sensory Impairment project (which itself was an extension of the BUPA Care Homes project) has been submitted to an external funder. The data from the original projects indicate that there may be a different *pattern of functional loss* in terms of Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) related to emerging dual sensory loss or the early impact of dementia. It seems that people in the former group *inhibit* some of their behaviors as a result of concern about their hearing and vision, whereas individuals in the latter group become *disinhibited* as a result of the loss of the sense of self that is characteristic of dementia. Discussions with Age UK about a collaborative project have been positive so the proposal is to compare the pattern of loss of ADL and IADL in a group of elderly people with dementia (recruited through Age UK branches) to the pattern of loss in elderly people with dual sensory impairment (recruited through Sense) with a view to developing a Screening Tool to support family members to identify the potential underlying reason for any changes in behavior they observe in their elderly relatives.

The initiatives described in this paper show how one organization responded to the need for robust evidence related to the impact of deafblindness across the lifespan. Undertaking this range of research has contributed to our understanding of the lifelong experiences of people who are deafblind and their families, and has demonstrated how organisations can use research to support deafblind people to achieve their potential.

For more information, contact Dr. Anna McGee, Head of Research, Sense

Email: anna.mcgee@sense.org.uk

¹ Presented as a workshop at the 16th Dbl World Conference in Bucharest, May 25–30, 2015

² Sense (www.sense.org.uk) is a large corporate member of Dbl

³ https://www.sense.org.uk/.../Sense_rubella_and_ethnic_minorities_project

⁴ <https://www.bupa.co.uk>

⁵ <http://socialhaptic.deafblindinternational.org>

The mental health and wellbeing of people living with Deafblindness: future directions for disability and mental health services

A PhD project: Alana Roy

How might we develop a better understanding of people who are Deafblind? The Deafblind population face complex and multifaceted social, political, and economic barriers as they attempted to navigate the world with limited, or no sight and hearing. Deafblindness can limit choices and opportunities in accommodation, education and vocational activities. It can confound personal care, orientation, mobility and safety, and negatively impact communication and social relationships. As a consequence of these multiple impairments and limitations, Deafblindness can have a major detrimental effect on a person's social inclusion and access to appropriate services and supports, their quality of life and wellbeing and, consequently their mental health (Heliport, Andre, Pierre, & Chamberlain, 2006; Vernon, 2010).

Given the preponderance of Deafblindness in the ageing population in particular, and the rise in the ageing populations around the world, there has been a growing interest in the assessment, treatment, and provision of support for Deafblind people (Brenna, Horowitz & Ya-ping 2005; Heine & Browning, 2002; Schneider et al. 2010). However, there is a shortage of skilled professionals who can work with, and communicate effectively with this population. Academics, governments, allied health professionals and disability service providers all need to be better equipped to respond to the needs of the growing population of Deafblind people (Ronnber & Borg, 2001). To assist with the development of appropriate policy and effective practice, a model is required which encapsulates the needs, priorities and aspirations of Deafblind people, and which can inform policy makers, practitioners, and those responsible for the development and delivery of services.

Since the 1970's, the *Bio-psycho-social model* of disability has gained popularity in the literature and social services. This model has since been adopted by the World Health Organisation (WHO) in their International Classification of Functioning Disability and Health (ICF; WHO, 2001). This model acknowledges the medical components to disability but places an emphasis on the socio-economical, physical, and political barriers that restrict disabled people (Engel, 1977; 1980). For the purpose of this review, when defining and developing an understanding of what constitutes Deafblindness, the bio-psycho-social model will be extended to the bio-psycho-social-cultural model. This model offers a holistic theoretical approach; incorporating knowledge from biology, psychology, and the social sciences. In addition, Bronfenbrenner's Ecological Systems Theory (1979) will be used to analyse the state of the research in the field of Deafblindness (i.e., within an

ecological context). It will be used to explore how organizations (microsystems), specific relationships (mesosystems), social settings (exosystem), cultural context (macro system), and environmental/socio-historical events (chrono systems) shape and influence the mental health and wellbeing of people living with Deafblindness (Brennan, 2005; 2007).

What do we know, and what do we need to know, about Mental Health for People who are Deafblind?

The field of Deafblind mental health is arguably in its infancy (Mathos, Lokar & Edward, 2011). Little is known about the psychosocial impacts of being Deafblind, and the associated mental health issues. Deafblind mental health and wellbeing is often overlooked or misdiagnosed, possibly due to the complexity of people's communication support needs. Further confounding the planning and provision of appropriate services, disability and mental health organizations generally do not record specific or comprehensive data on persons who are Deafblind, their mental health and wellbeing (Heine, 2014).

To inform developments in the field of Deafblind research, policy and practice, there is an established body of knowledge demonstrating that mental health is a central component of what Cummins (2005) refers to as *quality of life*; defined as "a state of well-being in which every individual realizes his or her own potential, can cope with normal stresses of life, can work productively and fruitfully and is able to make a contribution to her or his community (World Health Organisation, 2013b, para.1). Some authors have noted that people living with Deafblindness experience reduced functional capacity as compared to their peers with and without disabilities, limited social inclusion, poorer quality of life, and higher rates of mental illness (Heine & Browning, 2004; Hicks, 1978; Horowitz & Reinhardt, 1998; Luey, 1994). However, the majority of the mental health related data has focused on *deafness* or *blindness* as single sensory impairments (Hershberger, 1992 & Wahl et al 2013). The combined psychosocial impacts of Deafblindness have been largely overlooked (Vernon, 2007; Heine, 2014). To date, the Deafblind population has received a paucity of research interest of internationally, and little if any within the Australian context (Heine, 2014; Dammeyer, 2015).

Why the Need for a Deafblind Research Agenda, and What Might it Investigate?

The Deafblind community in Australia, and internationally, is characterized as unique culturally and linguistically diverse minority group. However, recognising the importance of being part of the wider society, they actively promote and pursue access, participation and inclusion in the wider community (Mathos, Lokar & Edward, 2011). Here though, with respect to addressing issues of social isolation and the associated mental health risks, it could be that being part of the Deafblind community itself decreases isolation and improves mental health and wellbeing (Mcletchie, 1997). Consistent with this proposition, there is some literature reporting on the benefits of Deaf culture on mental health and wellbeing(Kendal, Gutman &

Rosenheck, 2008; Lane, 1989; 1999; Lane, Hoffmeister & Bahan, 1996; Peters, 2007).

However, there is no published literature reporting on the more integrated holistic bio-psycho-social-cultural experience of people living with Deafblindness; how do they live, cope, adapt and thrive? Furthermore, there are limited data outlining how organisations, policies, procedures and staff might promote the mental health and wellbeing of people living with Deafblindness. Consequently, there are no current clinical best practice guidelines regarding how to work with Deafblind people effectively in a mental health context.

The current review will therefore critically summarise and establish the state of the science in the field of Deafblindness, focusing specifically on the *bio-psycho-social-cultural experiences* of people who are Deafblind, and how these factors might interact with, and affect mental health and wellbeing. These findings will then inform a research agenda, to be implemented with the ultimate goal of improving the mental health and wellbeing of Deafblind people.

Overall, this review addresses the question, to what extent a contemporary bio-psycho-social-cultural model might be useful when seeking to assess, treat and support people who are Deafblind and who experience mental ill-health?

Consequently, the questions driving the current review of the state of the science in this field are: what do we know about the clinical issues effecting and reflecting the mental health of Deafblind people; what do we know about the quality and effectiveness of organisations and services available to support Deafblind people; is there evidence of a distinct Deafblind culture and community, and if so how this might interact with and affect the mental health of Deafblind people?

This programme of research, based on issues identified through the systematic literature review, will:

1. Establish what constitutes the Deafblind Culture, in an Australian context, and how it is expressed;
2. Ascertain if, and if so how, Deafblind culture might affect mental health and wellbeing within this population; and subsequently the mental health priorities for this population; and
3. Devise and pilot strategies (e.g., policy, professional development and interventions) to address these issues.

Alana Roy (Mental Health Social Worker, Associate Member of the Australian Psychological Society and PhD Candidate, University of Melbourne, School of Social and Political Science). Alana's Principal PhD Supervisor is Associate Professor Keith McVilly (University of Melbourne) and Associate PhD Supervisor is Professor Beth Crisp, Deakin University.

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Manifestations of Congenital Rubella syndrome in Canada: a follow-up study

Stan Munroe

The Canadian Deafblind Association (CDBA) National Office¹ recently completed a follow up to its survey of the late emerging manifestations of congenital rubella syndrome in Canada published in 1999². This article³ presents some extracts from the full report, including the study rationale, description of the sampling method and a few tables of the findings. The full report will soon be available on the CDBA National website.

Study Rationale

The rationale for conducting this follow up project was to verify the previous findings as well as report any changes to the late manifestations over a period of fifteen years.

Sampling Method

Volunteers known to have CRS in Canada were sought through contact with various independent living residences for individuals with deafblindness and others known to have CRS and living elsewhere in Canada. Participants were asked to report (via a questionnaire) the incidence (including an approximate age of the onset) of observed manifestations affecting each individual's sensory, neurological, vascular, musculoskeletal, endocrine, respiratory and gastrointestinal system. In addition, a sociological snapshot of the participants was provided through answers to questions related to their level of communication and education, employment and accommodation history.

General demographics of the sample

Fifty-three individuals (29 males and 24 females) ranging in ages 29 to 62 years participated in this follow-up study. This compares to 100 who participated in the earlier 1999 study. Seventy percent of the current individuals were born during the period 1966–1980, corresponding to the period before rubella in Canada was largely contained through immunization programs.

Reported incidence rate of 'early onset manifestations'⁴ from the sample of 53 individuals with CRS

Vision Loss (Congenital cataracts)	96.2%	Hearing Loss	92.5%
Combined Vision & Hearing Loss	88.7%	Cardiac Defect*	64.0%
Combined Vision loss, Hearing	64.1%	Cardiac surgery	27.0%

Loss & congenital cardiac defect			
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* Cardiac defects reported included: heart murmur (31.4%), patent ductus arteriosus (28.6%), pulmonary stenosis (28.6%).

Reported incidence rate of 'delayed manifestations' ⁵			
Glaucoma (n=47)	53.2%	Corneal damage (n=42)	28.6%
Detached retina (n=42)	21.7%	Late onset change in hearing (n=36)	25.0%
Hypertension (n=50)	18.0%	High cholesterol (n=50)	20.0%
Respiratory problems (environmental allergies, lung problems and pneumonia) (n=51)	52.9%	Allergies to various drugs (n=51)	35.3%
Such spinal conditions as scoliosis or kyphosis (n=51)	19.6%	Diabetes (Types 1 &2) (n=52)	21.2%
Thyroid dysfunction (hyper and hypo-thyroidism) (n=52)	43.2%	Various gastrointestinal issues (n=53)	50.9%

Reported incidence rate of Neurological Impairment from a sample of 51 individuals with CRS			
Reporting all neurological issues	49.0%	Incidence of seizures	27.5%
Signs* of motor skill degeneration	27.5%	Demonstrating at least one sign of cognitive degeneration	33.3%

* Signs of cognitive degeneration reported were: poor attention and distraction, disorientation, impaired short term memory loss.

Reported incidence rate of Psychosocial Behavioural Issues			
Stereotypical behavior (n=47)	72.3%	Self-injurious behavior (n=52)	71.2%
Compulsive behavior (n=50)	42.0%	Ritualistic behavior (n=51)	56.9%
Sameness behavior (n=49)	44.9%	Restricted behavior (n=47)	34.0%
Aggression to others (n=52)	51.9%	Episodes of anger or rage (n=52)	69.2%

Reported incidence rate of Signs of Depression

Reporting signs* of depression (n=47)	20 (44.7%)	Rate of change in signs of depression in past year: Increased (10.6%); Decreased (36.8%) Remained the same (52.6%)
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* Signs of depression reported were: appearing depressed; avoiding social contact, crying frequently, not taking part in activities once of interest; appearing restless or fidgety; complaining of headaches or other aches and pains; eating too much or too little.

According to Dr. Jude Nicholas⁶ the reported signs of decreased mood (or depression) of individuals in this study could be associated with the reported psychosocial behavioural issues. These emotional problems related to regulation issues may affect the deafblind person`s capacity to regulate their emotions or emotional responses. Emotion dysregulation in turn may lead to increased social isolation, escalation of aggressive-disruptive behaviors and high levels of negative affect such as depression.

Discussion

The findings reported in the complete follow-up study not only validated the results from the previous study but demonstrated higher rates of incidence of later manifestations for many of the medical conditions examined. Examples reported include: the incidence of glaucoma (54.2% in 2015 versus 32.3% reported in 1999); the incidence of hypertension (18% in 2015 versus 7.2% in 1999); and the incidence of endocrine dysfunction (42.3% in 2015 vs 21.2% in 1999); over twice as many individuals showed indications of cognitive skills degeneration in 2015 compared to 1999.

Difficulties with behavioural or psychosocial control were similar between the two surveys, confirming the link of these behaviours to emotional disorders observed in individuals who are congenitally deafblind, according to Dr. Jude Nicholas.

This observation would suggest that, like the similar incidence of seizures (27.5% in the 2015 survey versus 30% in 1999), the difficulties with behavioural control are established congenital issues that appear as late onset manifestations.

Final comments

The data contained in this study confirms that congenital rubella syndrome is a devastating disease that continues to manifest itself throughout the life of the individual.

Based on the extent of the medical conditions reported in this sample of the CRS population, it is important that individuals with CRS be monitored closely for changes in their physical and emotional health.

While mandatory rubella immunization programs adopted throughout the world has sharply limited its impact, it is critical that these efforts continue unabated. Further, mandatory immunization initiatives must be expanded to blanket all of Eastern Europe, Africa and Asia if there is any hope of ensuring that children and eventually adults will not face the medical crises that this virus creates.

For more information contact Stan Munroe, CDBA Rubella project leader
(munroes@seaside.ns.ca)

¹ www.cdbanational.com. The Canadian Deafblind Association is a small corporate member of Dbl.

² A Survey of Late Emerging Manifestations of Congenital Rubella Syndrome in Canada. The Canadian Deafblind and Rubella Association, 1999.

³ Presented in a modified form as a poster presentation (May 28, 2015) at the 16th Dbl Conference, Bucharest Romania

⁴ Those manifestations reported in newborns or as very young children.

⁵ Those manifestations reported as developing during later childhood or progressively through adulthood.

⁶ Dr. Jude Nicholas is a Neuropsychologist living in Norway. (Email: jude.nicholas@statped.no)

Country news

Australia

Deafblindness and Mental Health

By Alana Roy – Mental Health Social Worker/Provisional Psychologist, Able Australia

An important part of my role as a Provisional Psychologist at Able Australia is¹ to facilitate a therapeutic and psycho-educational mental health support group for Deafblind people. The aim of the group is to provide a safe place for participants to share their thoughts, feelings and struggles. In addition, the group aims to inspire a culture of Deafblind advocates and role models who can offer support and share information with Deafblind people who may be experiencing mental health issues. The group convenes once a month for two hours, allowing participants to access individual counseling, email, and phone support. Participants are encouraged to pick their own topics for discussion and share the role of group facilitation. It draws upon a range of therapies and theories from social work and psychology. For example, cognitive behavioral interventions, emotion focused therapy, mindfulness, and acceptance and commitment therapy, grief, and loss and trauma models. Participants are encouraged to be authentic and open about any issues they may be facing.

What do we cover?

- Self-esteem and assertive skills
- What is empowerment?
- Grief and loss associated with Deafblindness
- Understanding anxiety and depression

- Self-care and relaxation skills
- Breaking down the stigma and shame associated with mental health issues
- Deafblind culture (the benefits and challenges of belonging to a unique community)
- Haptics workshop brainstorming mindfulness and meditation techniques
- Mindfulness tactile sensory workshop (specifically aimed at reducing stress)
- Sharing of skills, resources and information related to coping with Deafblindness

What our group members have said

“It taught me that every issue we have is something we need to talk about and share so that we can learn what is the best alternative to cope, manage an issue or even how to face the barrier we had.”

“I did like discussing topics and hearing others point of view.”

”I loved many topics but the main thing I have learnt from this session is that all the negatives or disadvantages are transformed to positives and advantages.”

“It has also helped me to develop new goals that I have dreamed about for many years. The best part was when everyone had their say and came up with some new words such as empower, inspiration, assumption and many more.”

For more information, contact Alana Roy at email:
Alana.Roy@ableaustralia.org.au

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

Bulgaria

The education of Betty

The education of deafblind students at the Prof. Dr. Ivan Shishmanov School for Visually Impaired Children¹ in Varna, Bulgaria began in 1989.

This article describes a particular case of our practice in training Sebatina (or Betty), a deafblind student, to become a more independent person and able to realize her full place in society. Her education is organized around three stages.

- During the first stage of educational training, Sebatina acquired basic mathematical knowledge, learned how to communicate with others through using

sign language and the tactile alphabet, and learned how to act appropriately in public places.

- In the second stage, also referred to as the “functional” stage, focus was placed on encouraging Sebatina to use the skills she acquired during the first stage in real environment situations, such as during visits to various public places such as shops, the pharmacy, the train and bus station, etc.
- Sebatina’s third training stage involved developing her occupational skills to work with ceramics, knitting, and in the school greenhouse.

For more information about the program, contact Lyudmila Petrova (Betty’s teacher) at: li_li1980@abv.bg

¹ www.varnaschoolfortheblind.org

Canada

The Senate of Canada declares June as National Deafblind Awareness Month

On June 26, 2015, the Senate of Canada¹ passed a motion to recognize June as Deafblind Awareness Month across Canada. This motion will help “to promote public awareness of deafblind issues and to recognize the contribution of Canadians who are deafblind.” It will additionally “recognize the strength, courage and dedication that deafblind people show every day in living their lives and facing their daily challenges.” June is the birth month of Helen Keller, an internationally recognized person who lived with deafblindness.

A planning committee with representatives from four organizations (Canadian Helen Keller Centre², Canadian Deafblind Association (Ontario Chapter)³, DeafBlind Ontario Services⁴, and Rotary Cheshire Homes Inc⁵.) are working together to create a national campaign to publicize this significant event. Their efforts include capturing attention from national media outlets and designing a distinct logo and tagline to help publicize an annual event celebrated coast to coast.

This committee has already drafted a Terms of Reference document and is encouraging organizations across the country to join their efforts, focused on celebrating persons who are deafblind in Canada and promoting an understanding about this dual disability. Forming effective partnerships, including relationships with government and key supporters is also of importance as well as ensuring a presence and inclusion for consumers who are deafblind.

Working collectively, we hope to provide consistent messages in order to increase awareness of the dual disability of deafblindness across Canada.

Karen Madho

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www.deafblindontario.com

¹ www.sen.parl.gc.ca/home-e.htm

² www.chkc.org

³ www.cdbaontario.com. The Canadian Deafblind Association (Ontario Chapter) is a large corporate member of Dbl.

⁴ www.deafblindontario.com. DeafBlind Ontario Services is a large corporate member of Dbl.

⁵ www.rotarycheshirehomes.org. Rotary Cheshire Homes Inc is a small corporate member of Dbl.

CDBA-Ontario celebrates its 25th Anniversary

Twenty-five years ago, a small group of individuals with a shared vision gathered to have the first board meeting of the Canadian Deafblind Association Ontario Chapter¹. The top agenda items were difficult and complex, as they focused on how this group would go about fundraising and bringing awareness to the disability of deafblindness as well as the need for Intervenor Services² to support adults who were deafblind. Some of whom were getting ready to leave the school system. This would be no easy feat.

But, with unwavering determination, a vision for the future and the dedication of volunteers, CDBA Ontario began to grow out of our humble beginnings. In twenty-five years, CDBA Ontario has become a respected leader in the provision of services to individuals who are deafblind and their families. There have been sixteen annual parent conferences, a name change and rebranding, the development of the CDBA Ontario Resource Centre³, and the current construction of a sensory garden and apartment complex. In addition CDBA Ontario provides adult Intervenor services throughout the province of Ontario to individuals who are deafblind in their family home settings, community settings and residential settings. Without a doubt, the catalyst behind all of our successes has been our vision statement that “All people who are deafblind will live rich meaningful lives.

Each of these milestones defines a dream that began twenty-five years ago. To celebrate, the Ontario Chapter of CDBA hosted a 25th anniversary fundraising gala with 150 guests gathered on November 14 2015 at the Chelsea Hotel⁴ in Toronto, Ontario.

Upon entering the Churchill Ballroom at The Chelsea Hotel, guests were delighted to see each table adorned with hand-crafted centerpieces created by a number of people in our services. No two centerpieces were alike as each person was encouraged to let their creativity flow and design something that represented the 25th anniversary of CDBA Ontario and what the organization meant to them. This special touch set the tone for the night as a subtle reminder of the importance of CDBA Ontario’s services and those who access them.

The evening began with a special performance that our guests will surely be talking about for some time. An open invitation was offered to those in our services to perform at the gala. Many were thrilled to be a part of the celebration! The performance included some people signing the words to “Together We Are One” by Canadian singer Serena Ryder⁵ and others were drumming to the beat of the song. Their commitment to practicing over the last couple of months with the assistance of CDBA Ontario Intervenors was endless and it showed. Though many were a bit nervous to perform in front of a large crowd, each person stood on the stage with confidence and pride. A standing ovation complimented this impressive, heartwarming performance.

Also performing live was 17-year-old Avery Williams who is deafblind. This talented young lady filled the room with her beautiful voice singing “Hero” by Mariah Carey, “Baby, I Love You” by Aretha Franklin, and “Stay” by Rihanna.

Cathy Proll, Executive Director of CDBA Ontario, took the audience on a journey through the past 25 years and ended her presentation with a beautiful slide presentation with pictures highlighting many of the different events and the people who have been apart of the organization over the years.

Excitement continued to fill the air as guests were able to take part in some fun fundraisers. Guests eagerly purchased chocolate bars for a chance to find two golden tickets. One prize was for two tickets to a Toronto Maple Leafs hockey game and the second was for two tickets to a Toronto Raptors basketball game. A silent auction, 50/50 draw, and photo booth were also part of the evening’s events.

Closing out the night was a speech from Anabela DaSilva, president of the Board of Directors and the parent of a child who is deafblind. Anabela described to a captive audience that when she found CDBA Ontario, she found an extended family. For her, and many of the families involved with CDBA Ontario, this meant that they weren’t alone. She described this moment as feeling an immediate sense of belonging to community that understood their struggles. This came at a crucial time for her and her husband Mike, as they had been searching for some time for services for their child who is deafblind. This is something she will be forever grateful for.

A heartfelt thank you on behalf of everyone at CDBA Ontario wrapped up an evening filled with joy and sentiment as Anabela summed it up by saying: “thank you for inspiring us, believing in us, and helping us build an organization that can continue to ensure that individuals who are deafblind will live rich meaningful lives.”

Photos of the 25th anniversary fundraising gala can be viewed at:
www.facebook.com/cdbaontario

¹ www.cdbaontario.com. CDBA Ontario is a large corporate member of Dbl.

² *Intervenor Services* are provided to both children and adults by our staff of trained professionals (Intervenors). Intervenors provide communication and information in the preferred mode of the individual who is deafblind.

³ An article about the Resource Centre was featured in the 51st edition of Dbl Review, July 2013.

⁴ www.chelseatoronto.com

⁵ serenaryder.com

Denmark

A little village called ‘the Globe¹’ – a basis for social connectedness

Two years ago I started a new job as a manager for a Residential home for 24 people with congenital deafblindness.

To many people this may sound strange to have 24 individuals with the same disability at the same place! Is this a totally opposite description of inclusion of people with disabilities? No I don't think so. I will explain my thoughts!

Our residential home facility consists of 3 buildings connected by glass-lined hallways; two buildings provide private living quarters, while the third is primarily staff working area. Each of the living quarter buildings have the same structure: two groupings of six private apartments, each apartment grouping sharing a sitting room and kitchen area. Each apartment is the individual's home, consisting of a private bedroom, living room and bath. The third building consists of a common area for meetings, offices for the managers and a massage room.

Most of the individuals prefer to eat together with their 5 other neighbours rather than being alone in their private apartment. Most also prefer to join in social contact in their shared living area. I know this appears to be like most other group homes throughout the world! The difference however is that they have the opportunity to visit and join in social contact among the 24 individuals living in the interconnected buildings.

At our residential home, there are 70 staff members. Many of them have worked with people with deafblindness for many years meaning that they have a wide range of knowledge and familiarity with many of the residents. The residents have the opportunity then to visit with staff members throughout the entire facility with whom they are familiar with and can share past experiences.

People with congenital deafblindness have special needs for communication and accessing social contact. Since few individuals in the regular population can provide these special communication needs, living in this setting provides a welcome opportunity for them to engage with a wide range of staff members and others who have that special knowledge.

Thus in ‘The Globe’ we can provide a wide range of opportunities for the individuals to choose socializing with others within the complex that they know and wish to share an interest with.

In a setting with 24 residents, the individuals have an opportunity to build friendships with so many different individuals living at the same place. Some friendships might consist of a cup of coffee, others might be romantic, some are founded in other common interests.

The fact that we are in the same building gives the residents opportunities to visit others across the hall without any help from the staff. Hence the social context is much wider as well as the opportunities for more relationships, inspiration and a sense of community involvement.

Therefore, in my opinion, the Globe, which provides an environment where individuals located together in the same place having an opportunity to make their own independent choices, is a prime example of inclusion – a human right.

Henriette Hermann Olesen
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¹ The Globe is Kloden in Danish language

² www.chd.rn.dk. Centre for Deafblindness and Hearing Loss is a small corporate member of Dbl.

India

Sense and Feel Nature

A Jungle Adventure Camp in India for the Persons with Deafblindness and Multiple Disabilities

We know that our senses evolved during the course of our human evolution in relation with the changing natural environment amidst which we live. What happens to us if we do not have one or more senses which, as human beings, we consider as normal? In reality we would never know what magic we miss.

A person who cannot see and hear, or has multiple disabilities since birth, never knows the experience of seeing and hearing. Those individuals who happened to lose one or more senses at some point in their life do understand the degree of sensory loss that cannot be replaced. They must depend on their tactile and olfactory senses to develop a working relationship with the environment and maintain their lives with dignity. We know from them that this new development is very difficult. We also know from them that without assistance from a trained person, they feel they are at a loss in society because their abilities remain almost hidden because of their sensory losses. In countries like India their problems are only compounded by the conditions of poverty, lack of knowledge of the community or family they belong to and the paucity of institutional or state level support which they need so much.

For more than ten years now, The Project Deafblind Society for the Visually Handicapped (SVH)¹, a partner organization of Sense International (India)², has been working in Kolkata (India) with these individuals with various degrees of sensory losses and multiple disabilities who come from widely different social strata. This Society, consisting of a few hard working members (mostly ladies), over the years demonstrated a high level of dedication in their chosen social cause. The Project Deafblind members and staff undertook to study the issues of deafblindness and educate themselves to develop a level of expertise to work with these sensory impaired individuals. Equipped with the required training and education they have undertaken various measures to rehabilitate these individuals through counseling

and encouraging them to participate in various recreational and vocational activities. Along the way the Project team established strong connections with various government, non-government and corporate organizations to obtain and develop resources for their work.

Recently the author had the opportunity to accompany the Project team to Chandak Dampara³, a forest zone in Odisha, the site chosen to hold its 4-day camp for students with various degrees of sensory deficiency. This camping project was organized in collaboration with the East Zone Committee of the Indian Mountaineering Foundation (IMF)⁴ and the Government of Odisha⁵.

Over 50 persons participated in the camping experience. Participants included individuals of all ages and at all levels of sensory disabilities and stages of rehabilitation as well as parents, teachers, other professionals and businessmen. The camp experience provided an excellent opportunity to demonstrate the level of mutual cooperation and trust that was necessary among all the participants of different age groups and levels of sensory disabilities.

The camp activities included different kinds of exercises and competitive events designed to build capacity in both physical and mental areas, including various sports such as rock-climbing and river crossing. The emphasis was always on making the students self-sufficient and disciplined. The events were successful in that while they entertained, they also benefitted both students and their teachers and guides.

The camp taught all concerned quite a few things. **First**, it is necessary to have the will to create and lead a meaningful life. This requires a mind-set that one should never give up. One's objective should be to set specific goals in life and use all available resources to fulfill those goals. **Second**, it is necessary that one should develop the will to convert a particular form of disability from a disadvantage to an advantage. For this, the remaining senses need to be cultivated as much as possible and used to their optimum levels. **Third**, it is necessary to keep in constant touch with persons of different levels of ability and organizations such as SVH to keep abreast of new developments in the field of sensory disabilities. **Fourth**, it is absolutely necessary for everyone to be clear-sighted, self-sufficient and dignified.

Two very important events occurred during the 4-day camp: a jungle safari in the wild life sanctuary, Chandak Dampara, and a visit to the twin caves Udaygiri and Khandagiri⁶ located close to Bhubaneswar⁷. Known for its splendour and pristine home to many species, the wildlife sanctuary contains a treasure trove of biodiversity. It is the habitat of elephants, deer, and wide variety of birds including peacocks. Udayagiri and Khandagiri Caves are partly natural and partly artificial caves bearing archaeological, historical and religious importance. Climbing the hills meant a strenuous exercise for many campers; yet their achievements were reflected in their facial expressions. Some of them learned the technique of climbing the high stairs for the first time – techniques learned easily with pleasure.

The evenings were reserved for highly informative documentaries on mountains and mountaineering, wildlife and different aspects of nature. Dipan Kolita, a fourth generation ***mahoot (elephant rearer)***⁸, absorbed all of us with his narratives about elephants and many of their behavioral features. Kolita illustrated his statements

with anecdotes and observations which reflected his encyclopedic knowledge of elephants,

It is always difficult to depart from places like Chandak Dampara. The last night at Chandaka was reserved for a camp fire. It was a wonderful sight with the students of different abilities putting on their best performances, including singing, dancing, telling stories and performing drama; a few of which were specially created for this occasion.

Congratulations to Project Deafblind for organizing this first adventure camp as a celebration of their 10th year in existence. Thanks to SVH Project Deafblind for their dedicated work with persons with deafblindness and multiple disabilities.

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For more information about the Society for the Visually Handicapped Project Deafblind, Kolkata, contact Ruma Chatterjee (ruma1@rocketmail.com).

¹ www.svhdeafblind.org; [facebook.com/svhdb](https://www.facebook.com/svhdb)

² www.senseintindia.org. Sense International (India) is a small corporate member of DbI.

³ chandakawildlife.in

⁴ www.indianmountaineeringfoundation.com

⁵ www.odisha.gov.in

⁶ https://en.wikipedia.org/wiki/Udayagiri_and_Khandagiri_Caves

⁷ <https://en.wikipedia.org/wiki/Bhubaneswar>

⁸ <https://en.wikipedia.org/wiki/Mahout>

⁹ www.vidyasagarcollege.edu.in

¹⁰ www.caluniv.ac.in

Ireland

The Anne Sullivan Centre, Dublin, Ireland

We are happy to announce it's been a busy year for us here at The Anne Sullivan Centre¹ in Ireland!

We hosted our 2nd Annual National Deafblind Awareness Day on April 18, 2015 in Tallaght Stadium in Dublin. Members of the Deafblind community from all over the country attended this event with their families. In addition to a display on how our Deafblind residents at the Anne Sullivan Centre communicate, we had a several local and national organisations exhibiting at tables surrounding the room such as DeafHear², the Irish Deaf Society³, Sharing the Journey⁴, Fighting Blindness⁵, Child

Vision⁶, and Ash Technologies⁷. The highlight of the day was our two speakers, Joanne Milne and Orla O’Sullivan. Joanne spoke about how losing her sight after growing up profoundly Deaf affected her but that she was very positive about life after getting fitted with a cochlear implant. She had copies of her newly released book entitled, *Breaking the Silence* (Coronet, 2015)⁸ which she signed for those present. Orla O’Sullivan, who is also Deafblind, shared her love of music as a renowned pianist and qualified music teacher. She played a beautiful piece by Beethoven which captivated all attending.

As a follow up to what was learned in last year’s research project, “*A Study into Deafblindness in Ireland*”⁹ The Anne Sullivan Centre has been working hard to raise awareness and get recognition for Deafblindness in Ireland. On May 28, 2015, members from the Anne Sullivan Centre along with professionals in the fields of audiology and ophthalmology, as well as Carol Brill, an Irish woman who is Deafblind, went before a joint Oireachtas (Irish Parliament)¹⁰ meeting on Health and Children to discuss recognising Deafblindness as distinct disability. The submission was met with much support from the T.D.s (Members of Parliament) that were present. As a result of the meeting, a letter has been sent to our Minister for Health, Leo Varadkar, as well as the Minister for Disability, Kathleen Lynch, as a call to action on the submission. We hope this means there will be some changes made as it is extremely important to our Service Users and members of the community who are Deafblind.

From everyone at the Anne Sullivan Centre, we wish the Dbl Community a happy, healthy 2016!

Deirdre Leech, Anne Sullivan Centre, Dublin, Ireland

For more information contact: info@annesullivan.ie; www.annesullivan.ie

¹ www.annesullivan.ie. The Anne Sullivan Centre is a small corporate member of Dbl.

² <https://www.deafhear.ie>

³ <https://www.irishdeaf society.ie>

⁴ sharethejourneyapp.org

⁵ www.fightingblindness.ie

⁶ www.childvision.ie

⁷ www.ashlowvision.com

⁸ www.amazon.ca › Books › Biographies & Memoirs › Memoirs

⁹ Reported in Dbl Review, Edition 54, January 2015

¹⁰ www.oireachtas.ie

Jordan

News from the Deafblind Unit at the Holy Land Institute for the Deaf in Jordan

Exploring the world with your hands is hard work. There are so many impressions possible, it is simply amazing. But we know and understand so little about it. Thanks to our deafblind children we can learn little by little how they feel the world and how they understand the things they touch around them. Keeping up with them, their creativity is a full agenda and brings back the memories of some very nice experiences.

After Asma', the (deaf) deputy head of the deafblind unit, graduated from the Educational Leadership Program at Perkins¹ in Boston and returned to the deafblind Unit, weekly training courses for our staff followed. All the teachers working in the deafblind unit have a diploma special education, but during their time of study there wasn't a single lecture about the education of children who are deafblind. The training courses are unique and the HLID² is the only place in Jordan and the Middle East that conducts such courses. Starting with some very practical experiences, the teachers get the chance to go deeper and deeper into the very broad field of educating children who are deafblind. Every little thing they feel and understand themselves brings them a tiny step closer to the child they work with. There are very funny moments but also much thinking in order to come to the realization that the responsibility as educators is huge.

Filled with new impressions and ideas from their own training, *theme-based teaching* was implemented and new activities were developed. Eid alAdha (Islamic Feast of sacrifice) is a very important feast and in order to help the children understand what was going to happen when they got home for the holidays, the theme "Eid alAdha" was introduced. During arts and crafts classes little sheep were made. But really happy were the children the day the deafblind unit made a trip to one of the fenced-off areas where sheep are held, to be sold for the feast. The children loved to pet the sheep and are happy with our own new little goat "Billy".

Getting close to the end of term, the next theme was Christmas. All the children participated in decorating the deafblind unit.

One afternoon there was a party in the deafblind unit and parents and relatives were invited. They could discuss their children and see what they had done, but they also met and shared with other parents. For some it is good to know that they are not the only parents with a deafblind child. Presents from Father Christmas were a nice touch to end this happy afternoon. Before going home for the Christmas break, we held a big party with everybody. Some of the deaf children practiced a short play with the children of the deafblind unit.

Also some of the older students who are deaf thought of a play, together with two deafblind adults, to teach the audience some important things about sharing with students who are deafblind.

After much rain and snow, it was good to feel the sun again. With every day it got warmer, hills became greener, flowers started to blossom and to smell. Spring time!, with ever so much to do: Flowers with different textures were collected, seeds planted, plants bought and taken care of. As nice as all that was, the Spring feeling really arrived, when the deafblind unit made a trip outside the HLID. Fields full with flowers were the perfect environment for the children as they could smell and touch

everything. Bouquets were made and after returning to the HLID the children brought them to staff members as messengers of spring.

Every year all the children from the HLID go on school trips. Of course the deafblind unit wouldn't miss it and they had a great day, with nice food, horse riding, visits to the zoo, and a visit to a fun park.

The fact that due to the lack of the two distance senses, our children at the deafblind unit miss things that we are often not aware of, occurred to us right after the long summer break. A couple of our foreign volunteer staff members at the deafblind unit got married during the summer. All the children and staff were happy with the newly married couple, except the children from the deafblind unit. Even though we have had teachers from the unit getting married, we never thought to celebrate it with the children. Weddings are a special and well-celebrated event here in Jordan. It was about time to work on the theme "Wedding". The children made different things like ties and veils, dressed themselves up like bride and groom, and made games with rings. The highlight was, when the deafblind unit invited the newly married couple to celebrate a Jordanian wedding where the children could touch the bride and groom, give the things they had made themselves as presents and enjoy cake and drinks. It was a very special and wonderful afternoon.

So we hope to keep improving and to continue on the long way for our children to go. There are still many questions and obstacles, daily situations that are hard, but each step will take us forward. Exploring the world with your hands is a beautiful but time-consuming experience, but best done as a team. Then all things become possible.

"Alone we can do so little; but together we can do so much." –Helen Keller

For more information contact Brother Andrew (hlid@go.com.jo)

The Holy Land Institute for the Deaf is a non-profit foundation located in Salt, Jordan, north of Amman, that provides educational and rehabilitation services for people with hearing impairment.

HLID is a partner of CBM (Christoffel Blindenmission)
www.cbm.org CBM is a large corporate member of Dbl.

¹ www.perkins.org/international/elp

² https://en.wikipedia.org/wiki/Holy_Land_Institute_for_the_Deaf

Kenya

Two voices, one dream*

Emma Wambui and Rebecca Murunga have personal experience of the challenges faced by people with disabilities in Kenya. In their role as Sense International¹ Ambassadors, they are using their knowledge and passion to increase support for deafblind people and their families – and create change across the country.

Emma lives in Nakuru County, around three hours north-west of the Kenyan capital, Nairobi. She lost her sight and hearing in 2008 – and it changed her world completely.

“What does it feel like to be a deafblind person in Kenya? It’s crazy. I immediately lost my two senses; they almost went away at the same time. My parents were totally confused; totally, totally confused. My friends could not understand me anymore and I had to look for new friends and explain to them how to treat me.”

The challenges Emma faces – those of isolation, loneliness and communicating with family and friends – are similar all over the world. But life in Kenya can pose other, terrifying risks.

“There is a big issue of rape cases in Kenya. And the people who are being targeted are persons with disabilities – especially the deafblind and people with mental health problems. It almost happened to me one day but I thank God because I was rescued by a good Samaritan. It’s so risky in Kenya.”

It is estimated that 17,000 people who are deafblind live in Kenya. Families of deafblind children face specific practical and emotional problems – and disability is still stigmatised.

Rebecca’s daughter Abigail is 19 and is deafblind. “Whenever I move around with my daughter, everything stops; everyone is staring at her,” she says. “Of course, there is sympathy but you don’t really want it. I want to take Abigail with me wherever I go but it is a challenge.”

One of the biggest issues that Rebecca faces is identifying and getting the support Abigail needs. This was particularly the case when Abigail was younger.

“There are times when I don’t really understand what Abigail wants because her communication hasn’t developed – because we had no support when she was little. Although she is 19, she struggles with simple daily activities; at home, Abigail spends a lot of time lying in bed, covering herself up.”

Sense International – a turning point

“Sense International understood Abigail, they knew how to reach out to her, and they had programmes that could help her,” says Rebecca, who is now coordinator of the Parents of Deafblind Organisation in Burgomo County. “They embraced our parents’ organisation and brought us together, which has helped us to deal with the challenges we are facing and learn from each other. At times you realise that your situation is probably better than you feel. And because of that you gather the courage to continue.”

Emma first got involved with Sense International through the Nairobi Support For Women programme. “If I didn’t meet Sense International, I don’t even want to imagine where I’d be...” she says. “Life felt hopeless but when I came into contact with them, that’s when I decided no, I have to live a positive life.”

This support gave Emma the confidence to forge a career in community development. “The platform I was given, the support, talking to my parents, talking to the people around me; it was life-changing. Meeting the team and other deafblind people in Nairobi gave me that courage.”

Campaigning for change

Rebecca and Emma are heavily involved in advocacy and raising awareness of disability – and both are passionate about improving life for deafblind people in their country.

“We’ve trained in advocacy and the rights of deafblind people,” says Rebecca.

“We’ve then been able to meet different government organisations and explain how they can help the lives of the deafblind people to be better and a little easier.”

“Currently, we have a bill going through the County Assembly: the Nakuru County Persons with a Disability Bill,” says Emma. “It is a huge document that covers many important issues; health, for example, because there is a lack of trained doctors and nurses who know how to treat and communicate with deafblind people. The bill also includes education, accessibility, access to information and employment. I hope it will be made law this year.”

For Rebecca, education is an issue close to her heart. “Education and schooling is very, very important. We worked with the Kenya Institute of Curriculum Development to develop a new curriculum programme that is now being used across Kenya.

Teachers have been trained to support children who are deafblind, and there is now an outline that all teachers use. Abigail is following this new curriculum and she is enjoying it very well!”

Emma and Rebecca are positive about the future, but acknowledge that there is still much that needs to change. “I know there are so many other deafblind people out there. People who are hoping and praying and crying for someone to come and give them hope and a reason to live, a reason to smile,” says Emma. “This is why Sense International’s work is so important; it gives people in Kenya hope.”

To find out more about Sense International’s work in Kenya visit www.senseinternational.org.uk/our-work/kenya

Early intervention is vital

Sense International’s Finding Grace campaign aims to screen 300,000 infants in Kenya and Uganda to ensure that deafblind children are identified and receive the support they need in the crucial early years of development. Rebecca explains the difference early support will make:

“Early intervention is so important. When Abigail was young I didn’t know about what help could be given to her. If I did, Abigail would be doing so much more than she’s able to do now.

The Finding Grace appeal will go a long way in helping deafblind children to be more independent, understand how to live with deafblindness and be part of the community. Because once a child gets that early intervention, they will be able to go

to school, they will be able to graduate on to vocational school, they'll be able to acquire a skill.

I really long that other families are able to get services early enough so that they don't have to go through what we have gone through. Once there is an early intervention programme, then it won't be as bad as it is right now in Kenya."

*** This article was originally published in the Summer 2015 edition of Talking Sense Magazine, a publication of Sense²**

¹ www.senseinternational.org.uk. Sense International is a small corporate member of Dbl.

² www.sense.org.uk

Netherlands

Meet Hedda de Roo

A young woman with deafblindness who graduated cum laude

Awareness campaign

Hedda is participating in a Kentalis campaign to create increased awareness in society. The media is used to reach people who are not likely to meet deafblind people. There still are plenty of preconceived ideas about deafblindness, but things are improving slowly but surely. Hedda has been telling people about deafblindness for years now, and other deafblind people are also active in the Netherlands. There have been numerous campaigns, but there still is plenty of ground to cover. One achievement would be if people who use a white walking stick (cane) were considered as common in society as people using a wheeled walker.

Scientific research

Hedda currently works as a psychologist in specialist healthcare to patients without sensory impairment. She hopes to be able to work with people with deafblindness in the future, and would like to carry out psychological research into Usher syndrome. During her training, she set up a foundation that encourages scientific research into deafblindness, with the objective to increase quality of life for deafblind people. As you can read, Hedda is pretty busy, but she still finds time for her fiancé with whom she intends to share her future and start a family. Living with deafblindness is not always easy and involves tough and difficult times and situations, but this does not keep Hedda from pursuing her dreams. Who knows what the future holds?

Russia

Synopsis of 16th European Rehabilitation and Cultural Week for the Deafblind

Moscow, August 03–09, 2015

The 16th European Rehabilitation and Cultural Week for the Deafblind (ERCW-2015) was one of the most important events for the Deaf-Blind Support Foundation¹ in 2015. It took place in Moscow and the Moscow Region on August 3–9th. It was the first time in history Russia hosted such a prominent international gathering for people with combined hearing and sight impairment. Launched in 1997, the ERCW is an annual event. The participants had a unique opportunity to travel to Russia and get to know its history and traditions, from its early days to the present.

The ERCW 2015 attracted more than 200 deafblind attendees from twelve countries including Belgium, the UK, Denmark, Finland, Germany, Hungary, Italy, Norway, Switzerland, Sweden, Kazakhstan and Russia. The opening ceremony was hosted at a country club. The Foundation's President Dmitry Polikanov opened the event with a welcoming address and awarded the winners of a literary contest for the deafblind. Prizes included laptop computers, tablets and smartphones.

Many participants managed to make new friends as early as day one in spite of the language barriers. All of the activities of the European Rehabilitation and Cultural Week offered deafblind interpretation as well as regular interpretation.

"I learned about the ERCW from the Helen Keller Club, a Belgian organization for deafblind people. I had always wanted to visit Moscow, and the Week's tightly packed program made it all even more exciting. We'll get to visit local facilities for the deafblind, as well as tour Russia's landmarks," says Tina, a deafblind delegate from Belgium.

On Day two of the European Rehabilitation and Culture Week, the visiting participants from twelve nations took a boat trip along the Moskva River, toured Red Square and Alexander Garden. The day culminated in a theatrical performance of *The Touchables*² at the Meyerhold Center³. This performance starring deafblind as well as regular actors was a joint project of the Theater of Nations and the Deaf-Blind Support or Con-nection Foundation.

On day three, ERCW participants visited Sergiyev Posad⁴, one of the Moscow Region's most beautiful cities. They had a tour of the Holy Trinity–St. Sergius Monastery⁵, a UNESCO World Heritage site, and got a glimpse of ancient Russia at the World of the Russian Village museum⁶. The day closed with a visit to the Sergiyev Posad Deafblind Orphanage, a beautifully located suburban facility that accommodates and educates over 200 children and teenagers with combined hearing and sight impairment.

On Thursday, August 6th, the participants made a trip to the Military Technical Museum in Chernogolovka⁷ and the Deafblind House in Puchkovo, which offers comprehensive psychological, social and spiritual rehabilitation to deafblind people from all over Russia.

Friday featured a tour of the Babayevsky Chocolate Factory museum⁸, home to the renowned Russian confectionery brand, where visitors were given an opportunity to make chocolate sweets with their own hands. This activity proved highly popular with deafblind participants, encouraging them to employ all of their available senses: feeling warm cocoa paste with their hands, smelling the various chocolate aromas, tasting the various fillings.

On Saturday, the participants traveled to the city of Zaraysk⁹ (Moscow Region) and toured its main landmark, the Zaraysk Kremlin – the smallest Kremlin fortress in Russia which is nearly 800 years old. Their visit fell on the same day with a historical reenactment festival, which drew hundreds of living history enthusiasts from all over Russia, and gave ERCW participants a chance to try themselves at ancient crafts such as blacksmithing, pottery or leatherworking, set up in recreated medieval environment, amongst costumed re-enactors.

Saturday night also featured a gala dinner for ERCW participants. All of the deafblind attendees were coming away with great memories of this year's European Rehabilitation and Culture Week.

"This was a very impressive week," says Geir Jensen, President of the World Federation of the Deafblind¹⁰. "We saw a lot of interesting things in Moscow, and also got to know the Moscow Region. We had many surprises, and the greatest one was how superbly ancient churches have been restored, as well as the Kremlin and Red Square. I also enjoyed the Russian cuisine. We have learned a lot here in Russia. When I go back to Norway, I will tell my colleagues about all the things people do in Russia, and I'm happy to say they do it all very well."

The Deaf-Blind Support or Con-nection Foundation also used this opportunity to test the accessibility of the museums and city infrastructure for people with dual sensory impairment. The observations and recommendations were discussed in September at the specially organized seminar comprising museum workers from nearly 40 regions of Russia. The ERCW-2015 experience will be considered when holding further events for the global deafblind community in Russia.

Alex Overchuk

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¹ so-edinenie.org/en

² www.tcm.com/tcmdb/title/559049/The-Touchables

³ https://en.wikipedia.org/wiki/Center_of_Theatrical_Arts_%C2%ABHouse_of_Meyerhold%C2%BB

⁴ https://en.wikipedia.org/wiki/Sergiyev_Posad

⁵ https://en.wikipedia.org/wiki/Trinity_Lavra_of_St._Sergius

⁶ http://www.musobl.divo.ru/Econst_mirrusder.html

⁷ russiatrek.org/blog/.../unique-military-technical-museum-near-moscow

⁸ en.travel2moscow.com › Where › Visit

⁹ <https://en.wikipedia.org/wiki/Zaraysk>

¹⁰ www.wfdb.eu. WFDB is a Dbl partner organization.

The archives of prominent Russian hearing and vision impairment specialists now available in digital format

The Russian Deafblind Support Foundation¹ recently released digitized archived materials from prominent Russian vision and hearing impairment specialists Ivan Sokoliansky² and Anatoly Mescheriakov³. The archives are now available for Russian speaking audiences on www.zagorsklibrary.org.

Part of the collection will be translated into English in the near future.

The archives are divided into three parts. The first collection is that of Ivan Sokoliansky and includes his personal and working notes, diaries of observations made during his work in Kiev as well as hand written copies of his published articles. The collection includes the full bibliography of Sokoliansky's written and published articles.

The second collection includes the notes of Dr. Mescheriakov, who introduced comprehensive methods for the rehabilitation of Deafblind people in Soviet era Russia. His accomplishments included: establishing the renowned Zagorsk School for Deafblind people, developing the Center of Excellence, a Deafblind college for undergraduate students and arranging employment opportunities for graduates from the college.

The third collection comprises the materials and diaries of Dr. Mescheriakov and his working team, created while working with four brilliant Deafblind students (known as the 'Zagorsk' four) during their studies at the Zagorsk school and later at Moscow State University. This collection also includes notes and works written by the students themselves.

Besides the written texts, all three collections contain rare images that provide a visual account of the history of Deafblind studies in pre-revolutionary, Soviet era and contemporary Russia. For example, there are pictures of Dr. Sokoliansky with his deafblind students, including Olga Skorokhodova⁴, photos of the children's orphanage in Kiev where Dr. Sokoliansky was working before his detention in World War 2, pictures of Zagorsk's School for the Deafblind and of Dr. Mescheriakov's laboratory, portraits of his Deafblind students working and chatting through the snapshots of their hand crafted artworks.

Dmitry Polikanov, President of the Russian Deafblind Support Foundation, indicates that these archives will expand in several ways over the next year. According to Polikanov, the entire digitized archives will be converted from the current image format into text format. As well, approximately 1000 items from the archive will be translated into English.

Notably, the archive will be enhanced in 2016 through the addition of the works of Avgusta Yarmolenko⁵, a student and colleague of Dr. Sokoliansky. Previously unpublished articles of Dr. Mescheriakov will also be added to the archive.

Regarding the importance of the archive to deafblind science, Polikanov said "this archive represents a significant contribution to the study of deafblindness and will help scholars all over the world in their further research into this condition".

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¹ so.edinenie.org/en

² van Sokoliansky was the founder of the Kharkov School for Deaf-Blind in Russia and developed the principle of shared activity in the rehabilitation of disable children. From Vygotsky's Psychology: A Biography of Ideas by Alex Kozulin .Harvard University Press 1990 (<https://books.google.ca>)

³ From Vygotsky's Psychology: A Biography of Ideas by Alex Kozulin .Harvard University Press 1990 (<https://books.google.ca>)

⁴ <http://encyclopedia2.thefreedictionary.com/Olga+Skorokhodova>. Olga Skorokhodova was one of famous Zagorsk Four educated at the Zagorsk School for the Deafblind.

⁵ Russian psychologist, defectologist, Doctor of Education, professor at Leningrad State University, expert in the area of research of deaf-mutism with blindness.

Summer Camps for Russian Deafblind children

The Russian Deafblind Support Foundation 'Con-nection'¹ organized two camps for deafblind children during this past summer of 2015. The first camp was attended by children with their families while the second camp hosted children with visual and hearing impairment from various Russian orphanages from Moscow District to Western Siberia.

The primary purpose of the two camps, held in the Russian Black Sea Region, was to provide the children with much needed summer rest and recreation. Activities included swimming with hydrotherapy specialists, animal therapy with dolphins, art therapy, breathing technique sessions. Other activities included consultations with psychologists and specialist teachers and workshops to build more effective communication between the children and their families and tutors. The camps also featured an important educational dimension, incorporating the work of prominent specialists on deafblindness.

The main goal of the first camp for deafblind children and their families was to offer a supportive, relaxing environment for families and to help them to learn more about communicating with each other, as well as expanding the range of activities they can all enjoy together.

The educational part of the program was developed by the Institute for Correctional Pedagogics². Young specialists came to listen to lectures given at the summer school and also had a chance to analyze the activities and behaviours of deafblind children and their families during their rest and recreation periods. At the end of the program, the student specialists submitted a paper of their observations and analyses. The results from their work were discussed with the Institute's specialists and further work was discussed and developed.

Another important result of the school camp was the new support network built by the parents of deafblind children. The families were able to share experiences and concerns, and were eager to develop relationships of sharing and support.

The main aim of the second camp was to improve communication of deafblind children from orphanages with their tutors who would spend the most time with them during the day. Besides practical consultations, tutors were given lectures by specialists from Sergiev Posad School for Deafblind³ on topics such as calendar system implementation and self-care skills development.

Sabina Savchenko, head of the 'World, Society, Family' program⁴, said "It was a real challenge for us to go through several important phases of work with children and guardians in the very short period of the time (10 days) that we had with them. There were psychological and special medical diagnoses to be made, correctional mental and physical development training sessions with experienced specialists, evaluations of interactions between children and adults and individual psychological and pedagogical consultations. The positive result of this intense program of work is the dramatic development we have witnessed in each of the participants of our camps".

¹ so-edinenie.org/en

² www.university-directory.eu/.../Institute-of-Correctional-Pedagogy-of-th...

³ <http://www.themoscowtimes.com/news/article/giving-eyes-and-ears-to-the-blind-and-deaf/240489.html>

Sergiev Posad School for Deafblind was once known as the Zagorsk School for the Deafblind

⁴ so-edinenie.org/.../programmy/mir-obschestvo-semya/

UK

Celebrating its 60th Anniversary

Sense – part of a social revolution*

Sense¹ is a unique organisation. It serves people with some of the most challenging disabilities, has always worked closely with families, and has its own particular history and culture, writes Colin Anderson.

But it has also been shaped by, and reflected, broader changes and developments in society – such as changing attitudes towards disability and the growth of the voluntary sector.

When we still hear, in 2015, about families struggling to get the right support for their child, or an older person not coping, it can sometimes feel like nothing has changed. But if we look back it is amazing how far society has come in the last 150 years. The voluntary sector has its roots in the 19th century. The NSPCC² for example, was set up in 1884 and its approach then is still highly relevant today. It identified a social problem (in this case, child abuse), looked for viable ways to help the victims, then campaigned for the government to adopt these methods – because only the state had the resources to deal with this on a national scale.

In the twentieth century this state social provision and spending gradually grew in areas such as housing, health and education. At the same time, a succession of

new voluntary organisations grew up, especially in the 50s and 60s, often started by women who responded to gaps in provision.

Sense – or the Rubella group as it was first known – was one of these. It was founded in 1955 by Peggy Freeman and Margaret Brock as a self-help and support group for families whose children who had been born deafblind as a result of their mothers catching rubella in pregnancy.

Attitudes to disability had also gradually been changing over the century, partly as result of men returning from the first and second world wars with physical disabilities and mental trauma. Some of these men were in the vanguard of campaigning against poor access and inequality and a 'social' rather than a 'medical' model of disability emerged. Eventually – in 1995, the Disability Discrimination Act³ was passed.

Those early Sense parents also had a battle on their hands. There was almost no help for them and little understanding of the impact of deafblindness. One of their first priorities was to share information about their children's needs so they set up a newsletter, still going strong as Talking Sense.

They also began campaigning, establishing allies, holding conferences, offering training and winning over hearts and minds. In the fifties their children had been described as 'ineducable' but very gradually they won the argument. The 1970 Education Act – which paved the way for special units to be set up – was the first breakthrough. The 1981 Education Act was another important step as it introduced the concept of disabled children having 'special needs' and the right to an assessment and statement.

By this time, those original children from the Rubella Group were growing up and, just like today, their parents were concerned about what would happen to them when they left school and where they could live in the future. Thanks to a successful appeal by the Magpie children's programme⁴ in 1974 our first residential and education centre was opened in 1980 for 12 deafblind adults at Market Deeping near Peterborough.

This reflected a sea change in society. For many years, people with all sorts of mental, physical and learning disabilities had been placed outside society – in large, bleak often Victorian institutions. One young deafblind man that Sense now supports for example, was kept sedated and tied to a chair because the staff didn't know how to cope with him.

As public opinion increasingly turned against these long-stay institutions the policy of community care was introduced and Sense responded. Our first group home in Market Deeping was followed by others in Edgbaston and by the end of 1999, Sense had 73 group homes throughout the UK, providing supported housing and further education.

Another significant change was that fewer and fewer children were being born with rubella damage as result of immunisation. However, developments in medical science meant that increasing numbers of children were surviving difficult births, syndromes and medical conditions so that today Sense supports many children who are multi-sensory impaired, often with considerable physical and learning disabilities as well.

In fact, Sense has broadened its scope and activities in numerous ways since we began. In 1983 we started working with people with acquired deafblindness, including those with Usher syndrome and – as people are now living longer – we have developed creative ways to help older people with dual sensory impairments to keep their independence and stay in touch.

We've also greatly extended our geographical range: Sense Scotland⁵ launched in 1985, Sense Northern Ireland⁶ in 1990, and Sense Cymru⁷ (Sense Wales) in 1993. Sense International⁸ began its work in 1993 and now helps to develop services for deafblind people in Bangladesh, India, Kenya, Peru, Romania, Tanzania and Uganda.

Today, Sense's activities are still enormously affected by broader forces and changes in society. New technology for example, is offering unforeseen opportunities for people to communicate and participate. And the new social care legislation has the potential – if properly funded – to improve the co-ordination of care for families, which has been a perennial problem.

Whatever happens in the next 60 years however, it is fairly safe to say that our world – and Sense's – will have developed in all sorts of ways that we would never have expected!

*This article was originally published in the Summer 2015 Edition of Talking Sense Magazine, the magazine of Sense.

¹ www.sense.org.uk. Sense is a large corporate member of Dbl.

² National Society for the Prevention of Cruelty to Children (www.nspcc.org.uk)

³ www.legislation.gov.uk/ukpga/1995/50/contents

⁴ [https://en.wikipedia.org/wiki/Maggie_\(TV_series\)](https://en.wikipedia.org/wiki/Maggie_(TV_series))

⁵ www.sensescotland.org.uk. Sense Scotland is a large corporate member of Dbl.

⁶ www.sense.org.uk

⁷ www.sense.org.uk

⁸ www.senseinternational.org.uk. Sense International is a small corporate member of Dbl.

Nordic Network on Cognition

Focus on opportunities for children who have deafblindness

“Everyone has to achieve their full potential. It's a bloody human right”, says Hans Erik Frölander¹ who has been the coordinator of the Nordic Network on Cognition since 2008. The network is facilitated by Nordic Centre for Welfare and Social Issues, an institution within the Nordic Council of Ministers².

The network's goal is to develop tests to assess the cognitive development of individuals with congenital deafblindness or those becoming deafblind early in life. The purpose of these tests include assessing the child's cognitive abilities to assist specialists to provide appropriate stimuli to enable the individuals continual development.

When we talk about cognitive functions we mean those processes which take place in the brain when we receive, process, and transmit information i.e, the ability to

think, feel, and learn. But how do we know which cognitive abilities the child has if they are born deafblind or become deafblind early in life? How do you examine a child who is unable to develop speech because of impaired sight or hearing?

There are many standardized psychological tests, but they are seldom usable for this group of children born with or have early childhood onset deafblindness, since those tests require functional hearing and vision, says Hans Erik Frölander.

We need special tools and guidelines to be able to make cognition assessments of people born with or with early childhood onset deafblindness. This is why the “Nordic network on cognition” was established seven years ago.

One reason we wanted to look at this question was that people with early onset deafblindness often have an additional diagnosis, for example intellectual disability or autism, says Hans Erik Frölander.

The higher frequency of intellectual disability and autistic disorders depends partly on the fact that some of those who are affected by deafblindness have another syndrome which includes intellectual disability. This developmental delay could also be explained by the lack of access to auditory and visual information leading to a lack of understanding how people think and feel. But according to Hans Erik another explanation for higher frequency of these diagnoses could be misdiagnosis due to a lack of competency on the part of those doing the tests.

The people who are testing might not have enough knowledge about deafblindness and not recognize the importance of sight and hearing, Hans Erik explains. Of course, it's serious if the diagnoses are not correctly identified since the child won't receive the proper support.

The network has laid out guidelines for how the tests should be done. It's a big step in our work, says Hans Erik.

The material is aimed at professionals who work with the testing of children with deafblindness. The aim is to increase competence among professionals to observe, describe and assess the cognitive abilities of those people with deafblindness.

Those who conduct the tests need to have the right tools to make a correct and fair observation of the child's level of development. If we get a good picture of the child's development level then we can provide appropriate stimuli to support their development, says Hans Erik.

If an accurate test is made, it can result in practitioners understanding the obstacles to each child's development. Knowing this, the child's physical environment can be adapted to help the child develop to their full potential. Part of this is developing proper educational methods to assist parents and care staff to interact better with these children. Adapting the environment through proper practices for each child will ensure better development.

The brain needs proper stimulation. The lack of appropriate stimulation often results in these children developing self-harming behaviours, says Hans Erik.

The network's efforts are about spreading the newly developed guidelines³ throughout the Nordic countries. One of the methods adopted by the network is training courses organized by the Nordic Centre for Welfare and Social Issues.

The goal is that more children with deafblindness will be tested in the right way as the first condition to be provided the proper opportunities to achieve their full potential. It's a bloody human right, says Hans Erik emphatically.

Prepared by Victoria Henriksson, Communications Officer, Nordic Welfare
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¹ Hans Erik Frölander is the coordinator of the cognition network. He works as a psychologist at Resurscenter Dövblind , a Resource Centre for Children and Young People with deafblindness. He is also a PhD student at Örebro University.

² The Nordic Council of Ministers is the official inter-governmental body for co-operation in the Nordic Region. (www.norden.org/en/nordic-council-of-ministers)

³ "Guidelines for Assessment of Cognition in Relation to Congenital Deafblindness": <http://nordicwelfare.org/Guidelines-for-Assessment-of-Cognition-in-Relation-to-Congenital-Deafblindness>.

The Nordic Network¹ on Cognition

This network, formed in 2008, consists of around 20 members, predominantly psychologists and educators from within the field of deafblindness, several of whom are also connected to universities. The membership is spread across the Nordic countries, Switzerland, the Netherlands and Great Britain. The network is facilitated by the Nordic Centre for Welfare and Social Issues².

The Cognition Network was established to involve the fields of physiology, neuroscience, cognitive and developmental psychology, social psychology, pedagogy and semiotics³. The starting point has always been one of practicality, about sharing experiences and developing competence.

It is difficult to assess the cognitive abilities of people with deafblindness.

Expressions are not easy to interpret, especially those with congenital deafblindness. While this project has been focusing on this sub-group, the network also examines those with acquired deafblindness, in particular studying their potential cognitive decline. Tools and analytical models are very much lacking in both cases. The project has therefore aimed to improve the competence among professionals to understand, observe, describe and assess cognitive abilities of persons with deafblindness.

As the tactile modality is of utmost importance in deafblindness, the network has also strived to increase knowledge about physical tactile cognition. The network strives to develop methods and guidelines applicable in optimal settings, thereby including knowledge about aspects of deafblind communication.

Network members are currently trying to adapt existing infant and child developmental scales to those with deafblindness. Other examples include: adapting a common memory test for the elderly to use for individuals with acquired deafblindness; preparing a checklist to record the tactile working memory for those with congenital deafblindness, and developing a special executive function screening test adapted for individuals with congenital deafblindness. The network

has also been taking steps towards an analytical procedure to evaluate social cognition in the context of tactile communication.

This developmental work will continue within the network, bringing together practical experiences from the field, theoretical knowledge and scientific findings. The network intends to transmit their new knowledge through various publications, conference presentations and individual exchanges.

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Perkins Latin America

Indigenous Peoples in Latin America

Perkins International Latin America and Caribbean Region supports the cultural identity of each population

María Antonia Vazquez and Graciela Ferioli

Among the many initiatives promoted by Perkins International¹ in the Latin American region, one has been to reach out to the most remote areas of Latin America provide services to those individuals identified with multiple disabilities and deafblindness living within the many cultures living there. These regions are populated generally by indigenous people whose traditions, beliefs and living conditions complicate the challenge to provide services to these individuals.

Through the past ten years of our work in the region, Perkins International has become increasingly aware that indigenous peoples, whose families have members with disabilities, lack appropriate support necessary to address their educational rights. This reality is framed in a wider and much more complex situation that is associated with the individuals' cultural identity and their situation of vulnerability. The words of Carmen Guerrero² and Ana Isabel Zapeta Velásquez (mother and representative of the Mayan population in Guatemala)³ shed light on stories that exhibit a reality which is becoming more apparent throughout the educational systems in Latin America.

Discussing the right to education in this context brings about everyday issues that are culturally sensitive, such as: traditional clothing that people wear, travelling to school, language, etc. In Guatemala, for example, the indigenous peoples are more concentrated in the interior of the country and are less visible in the capital city of the country.

Guatemala has worked hard through legislation and the work of its disability organizations to promote awareness of their history, culture, beliefs, society, etc. One example of this is the issue of clothing. Some families still argue the right for

their child to wear traditional clothing while in school, while the school may require a special uniform. In other cases, there may be a generation gap within a family, such that the parents wish their children to wear traditional garments, while their children may choose modern clothing.

Consequently the educational organizations are learning to adapt to situations like this. Carmen Guerrero has reported that schools which demonstrate greater respect for the cultural diversity of the country see results with better participation from the indigenous families. However, the relationship with indigenous families is not always that perfect, often for reasons related to language and communication. Guatemala has 25 languages that are spoken among the different indigenous populations. To support the policies of inclusion, the Guatemala Ministry of Education⁴ uses four languages for their teacher training. This is not always the total solution, since there are many cases where the teachers hired do not know the specific language of the community in which they have to work. Successful communication with the child cannot be accomplished in these situations where the student (and parent) is illiterate, does not know the Spanish language and the teacher does not understand the indigenous language.

Further to language and communication conflicts, different beliefs about disabilities may affect service delivery. For example, one culture may look at a disabled child as a valuable gift, while another may view a disabled child as punishment. Differing beliefs are also observed regarding medical care. Some cultures put traditional remedies ahead of advanced professional medical care. Granted, some traditional methods may be effective; others possibly more life threatening. According to Carmen Guerrero, "Here, kids still die due to a diarrhea or dehydration and because people have no trust in doctors they rule out all other possibilities before even considering a visit to a professional physician or receiving medical assistance". Even within a family, one parent may approve of medication for epilepsy; while the other believes the medicine will do more harm.

Having said all this, because of the potential conflicts inherent in developing inclusive educational proposals for these indigenous people, it is important that cultural diversity must be seriously respected. Educational plans need to be developed with greater flexibility to account for different cultural traditions. It is important that the multicultural diversity of the Latin American people be more clearly understood by the country's educational system. Carmen Guerrero argues that by understanding and respecting the particular culture of the people that we are working with, only then will we succeed in satisfying the needs of all students evenly and according to their individual needs. Thus it is important to make adjustments specific for each different cultural community to ensure that the service is delivered appropriately.

Educational communities, indigenous peoples and disabilities

It is important to understand that the relationship between the educational facilities and disabled indigenous communities vary from country to country. "In a country like Bolivia, there is not common approach, just different stories and experiences, according to Alicia Rosaz⁵, Perkins International consultant. Despite the variety of

languages which pose great limitations on the school staff's ability to generate quality interactions, she affirms that the parents are amazing – they help each other and understand what they are asked to do”.

The vulnerable situations in which these people are living depicts two realities for this population with multiple disabilities and deafblindness. On one hand, there is the school community that provides care and nourishment for their child to allow the parents to work; on the other hand, there is the home and the strength of the family and how they deal with their child's disability including the initiatives they take to help their children. Alicia Rosaz says, “... *it is impressive how intuitive they are, how they organize their houses to improve access for their children; they put together parallel bars with trunks so that their child does not have to crawl – nobody taught them that; let's not forget that their situations are very unfavorable. We encounter parents who do not know how to read or write, and there are cases of parents with intellectual disability who themselves have children with multiple disabilities.*”

Once again the difficulty imposed by the lack of a common language becomes the main reason for the gap between the need for service and the kind of service that we can deliver. Alicia again states, “*the main problem for these people is that they do not speak Spanish, they speak different languages, not only one; these languages are not written and sometimes there are no words to define particular situations. One time a director asked the parents what they would you call a man who had autism-type characteristics. As this meant nothing to them (the word did not exist in their language to define the situation of their child), the parents answered “an isolated man.*”

People living in these vulnerable environments, receiving inadequate nutrition and exposed to many diseases, are subjected to higher rates of mortality and disabilities. In these situations there is a critical need to work on early intervention services to ensure a better development for these individuals.

Diversity, culture and curriculum

Throughout the ten years working with and learning about these diverse cultures, new best practices have started to emerge from Perkins International. These practices are supported through the philosophy favoring student diversity over intolerance, recognizing cultural and racial differences as strengths, not as weaknesses.

To develop this new approach which respects different individualities is both a challenge and an opportunity to learn about the diversity. This diversity must be considered when developing the curriculum plans.

To develop a new curriculum, educational plans must take into account the individual needs of each student with multiple disabilities and deafblindness as well as their cultural individuality.

During the last ten years of continuous activity with the indigenous population, Perkins International has been working to create educational options that reflect this diversity. It is a requirement now to show respect towards other cultures if we are to expect effective family, school and community inclusion. This means being flexible

with the educational curriculum, sensitive to modes of delivery and the location for the educational programs.

Allison's story (which follows) reflects how Perkins International Program promotes family, school and community inclusion and respecting the cultural identities of a specific Latin American and Caribbean people.

Allison is a charming six year old. She stands out in her community with her long black straight hair and her unique interpretation of music. She comes from an indigenous family living in one of the townships in the department of Chimaltenango, Guatemala⁶.

A month after she was born, her parents upon noticing that she did not open her eyes, took her to their health center. Upon hearing from the doctors that she was blind in both eyes, the family sought help. After learning about FUNDAL (Guatemalan Foundation for Children with Deafblindness and Multiple Disability), the family saw the opportunity for her to become independent and study like her two older brothers.

When she was three years old she joined FUNDAL at their Guatemala City headquarters. Initially only used to interacting with her family, Allison soon developed a level of social, living and communication skills which allowed her to achieve an appropriate level of personal independence.

Today she is six years old and is getting prepared to continue her studies in a regular school two hours from her home. While her parents are anxious, they are at the same time very happy with the opportunity that Allison has for developing further her educational skills and above all for enjoying living with other children of her age. The faith and encouragement from her parents has been very valuable and serve as an example for parents of the FUNDAL family.

There is no doubt that in Allison's short life she has showed optimism at every moment; her culture is part of her personality and by just watching her, listening to her sing or watching her smile, you can see that she transmits a feeling of peace that makes this world a more humane one.

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¹ Perkins International Latin America is a small corporate member of Dbl. (www.perkins.org/international/latin-america)

² Carmen Guerrero is the Pedagogical Director of Fundacion Guatemalteca Para Ninos con sordoceguera Alex-FUNDAL (Guatemalan Foundation for Children with Deafblindness and Multiple Disability)www.fundal.org.gt

³ Ana Isabel Zapeta is in charge of Administration at FUNDAL.

⁴ www.ieq.org/pdf/Guat_Status.pdf

⁵ Alicia Rosaz de Picasso Cazon is a mother, President of Instituto para Multi Impedidos Sensoriales (Fatima) and Past President of Organizacion Nacional de Padres de Personas con Sordoceguera y Discapacidad Multiple de la Republica Argentina.

⁶ <https://en.wikipedia.org/wiki/Chimaltenango>

International approach strategies to strengthen the EFAVI campaign in Latin America

Rocío López M.

The Global Campaign “Education for all children with visual impairment” – EFAVI is a global program of the International Council for Education of People with Visual Impairment (ICEVI)¹ that, acting in partnership with the World Blind Union (WBU)² and backed by UNESCO³ and UNICEF⁴, promotes the access of children and youth with visual impairment to an inclusive and high quality education. This can be achieved through the joint efforts of international bodies and consequently, thanks to the mobilization of resources in support of programs and services in favour of the visually disabled population whose education is in process.

Among other goals, this campaign cooperates with the developing countries in the world to increase inclusion in education centres, enhance educational performance, diminish school dropout and optimize the access to equipment and materials for the blind.

In 2006, Latin America answered to this proposal by constituting a Regional Working Group (RWG) with the participation of the following organizations: ICEVI, CBM International⁵, Perkins International⁶, the Latin American Union of the Blind (ULAC)⁷ and the Solidarity Foundation for Latin American Blind Persons (FOAL)⁸ of the Spanish National Organization of the Blind (ONCE)⁹.

As the world financial crisis increased in this new millennium, on September 11 and 12, 2013, the RWG held a meeting in Buenos Aires, Argentina, in support of the achievement of regional goals. It aimed at “discussing approach strategies to strengthen the development of the EFAVI campaign in Latin America as well as the links among partner organizations and the maximization of resources.”

The following representatives of the partner organizations participated in the meeting:

- ICEVI

Lord Colin Low (World President), Lucía Piccione (World 1st Vice President), Cristina Sanz (Regional Chairperson, Latin America), and Imelda Fernández and Fernanda Oliva Rizzi (EFAVI Country Coordinators)

- CBM

Martin Rupenthal (Latin American Director) and Rocío López (Consultant and Coordinator of EFAVI countries)

- FOAL

María del Carmen Peral Morales (Technician for Latin American projects), since Fernando Iglesias, Director, could not be present due to unforeseen family circumstances that forced his return to Spain.

- PERKINS INTERNATIONAL:

Steve Perreault (Latin America and the Caribbean Coordinator), Graciela Ferioli (Latin America and the Caribbean Regional Representative) and María Elena Nassif (Advisor).

- ULAC:

Volmir Raimondi (President), Lucía Pestana (Education and Culture Secretary).
Judith Varsavsky (interpreter).

Two important agreements were adopted:

The first one was about the legalization of ICEVI Latin America. Cristina Sanz, Regional Chairperson, worked with the lawyers Mariano Godachevich (Argentina) and Víctor Hugo Vargas Chavarri (Peru) on a proposal that she had submitted to ICEVI EXCO, and is now being studied by ICEVI President.

The second one was the development of an EFAVI Latin American Strategic Plan 2013–2016. Each partner organization nominated a technical representative to accomplish this task and the group was initially constituted by:

- Cristina Sanz and Lucía Piccione, ICEVI.
- Graciela Ferioli, Perkins International.
- Lucía Pestana, ULAC.
- María del Carmen Peral Morales, FOAL.
- Rocío López, CBM.

Helen de Bonilla was subsequently included in the group as a family representative.

Taking into account that these persons live in different countries (Argentina, Venezuela, Costa Rica, Guatemala and Spain, respectively), they are working on line, via Skype.

They started by developing a diagnosis of the situation through the SWOT mechanism¹⁰ and as a result, the decision of working on the following priority issues was taken:

- Communication, information and dissemination of information in order to integrate and enrich the region.
- Teamwork in order to increase the active participation of organizations of persons with disabilities and families.
- Advocacy of public policies that strengthen the coordination with governments and the compliance of the Convention on the Rights of Persons with Disabilities¹¹.
- Detection, since it is necessary to increase the timely attention of the needs of the target population.
- Low vision, to promote appropriate approach strategies to take care of the needs of the target population.
- Provision of resources and optical and non optical aids to cover the needs of the target population.
- Multiple disabilities and deafblindness, to increase their participation in the campaign.
- Capacity building and professional training, since it is essential to take into account methodological strategies to approach the education of persons with visual impairments.
- Early intervention, since the promotion of strategies to include these services in the educational system is required.

- Childhood and gender protection are aspects that require being strengthened in the region.

Taking into account these issues, the following strategic objectives were adopted:

1. Communication, Information and Teamwork

- To promote teamwork (information, communication, articulation, dissemination of information, coordination).
- To identify persons with visual disabilities, multiple disabilities and/or deafblindness through other national and international bodies that work in the EFAVI focus countries so as to increase together the outreach and quality of EFAVI
- Internal communication (National Working Group – NWG and RWG; external communication (with the civil society by means of websites, incidence in public policies, childhood and gender protection) and detection (in coordination with health, social welfare and other services) are taken into account.

2. Training and Capacity Building

- To contribute to the training and capacity building of the social actors that have to do with inclusive education of children and youth with visual impairment, multiple disabilities and deafblindness, in the EFAVI focus countries.
- To offer training opportunities about the rights of persons with disabilities in collaborative work with professionals, families and persons with disabilities themselves.
- To provide awareness and training by collaborative teams constituted by families, persons with disabilities, professionals and governmental authorities, in order to achieve empowerment and policy incidence that will ensure the exercise of the rights of persons with disabilities.
- To share information with governmental and non-governmental bodies about non-identified populations.
- To foster the establishment of higher and/or university degrees to approach visual disability, multiple disabilities and deafblindness.
- To encourage the inclusion of attention to diversity in higher education and university degrees.
- To share information with governmental bodies to achieve the inclusion of early intervention in the education system, as well as to provide opportunities of continuous training and capacity building.
- To share information with governmental and non-governmental bodies about the vulnerability of this population.
- To share information with governmental and non-governmental bodies to achieve the consideration of low vision as a unique condition with specific needs within the field of disability.
- To provide continuous training and capacity building opportunities.

The target population include teachers, technicians, the civil society, youth, families and organizations of persons with disabilities, as well as authorities.

3. Access To Technology

- To make the best use of information and communication technologies (ICTs) for the benefit of operation and interaction among the members of EFAVI Campaign (NWG and RWG), as well as to generate and circulate information to contribute to monitoring and achieving success in the actions developed in the framework of the EFAVI Campaign.
 - To encourage the use of low cost technology and the production of technical instruments with recycled material to contribute to the quality of life of children and youth with multiple disabilities and deafblindness.
 - To promote the quest of technical and technological resources through the campaign focus country governments and by means of international cooperation agreements.
 - The priority axes are ICTs, production and distribution of low cost technology with recycled materials and provision of technical aids (optical, auditory, augmentative and alternative communication, mobility).
- As of February 2015, we are working on the definition of strategies, deadlines and responsible persons of each goal.

To wind up this report...

This has been a process of learning and getting reward; it has enabled us to get to know each other better, to find a common path of sharing instead of competing, to join efforts for the benefit of a Latin America with greater and better opportunities. As Abraham Lincoln so wisely said, "If we could first know *where* we are, and *whither* we are tending, we could better judge *what* to do, and *how* to do it." And following Helen Keller's inspiring example of perseverance: "True happiness is not attained through self-gratification but through fidelity to a worthy purpose."

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¹ icevi.org. ICEVI is a Dbl partner organization.

² www.worldblindunion.org

³ en.unesco.org

⁴ www.unicef.org

⁵ www.cbm.org. CBM is a large corporate member of Dbl.

⁶ www.perkins.org

⁷ www.uladigital.org

⁸ www.foal.es

⁹ www.once.es. ONCE is a large corporate member of Dbl.

¹⁰ www.cultivate-em.com/uploads/business-tool---swot-analysis.pdf

¹¹ www.un.org/disabilities/convention/conventionfull.shtml

Adapted Physical Education

APA unlocks potentials

Adapted Physical Activity (APA)¹ brings joy and pleasure to physical education. The students experience independence, empowerment and equality regardless of their level of function. And they take those experiences with them when the lesson has finished. However, in order to further develop APA and the advantages of this method, it is necessary to cooperate at an international level.

By Anders M. Rundh and Mads Kopperholdt, the APA team at the Centre for Deafblindness and Hearing Loss (CDH)², Aalborg, Denmark

How do you inspire deafblind students to do sport, make new friends across various levels of function and to develop communicatively while at the same time creating an innovative and exciting teaching environment?

These were some of the questions we were pondering back in 2008 after having participated in a conference on APA in Torino, Italy. As physical education teachers both of us are inspired by the informal spaces created in sport activities and by the fact that based on this you can create relationships and thus prepare the ground for a common understanding and communication.

How APA works at CDH

This concept for our teaching is based on two principles of equal importance: the sporting element and the social element. From the start, our thesis was that by building a social solidarity between the students we would create a forum where the students would learn from each other and where the adults would be used as tools rather than as a point of contact and communication.

As physical education teachers we focus our efforts on adapting physical education to a group of deaf and congenitally deafblind children in the APA class at the Centre for Deafblindness and Hearing Loss (CDH). The project has only been running for a few years but we have already experienced some very positive results:

- **Communicative competences**

Students are using new signs and gestures not only during the lessons but also in contexts other than APA.

- **Increased social competences**

Students approach each other more frequently, also in contexts other than APA. Students seem happy to see each other again.

- **Increased knowledge of their own bodies**

Students display more ways of moving in their movement pattern. Their motor skills are improved and the students are able to work at different levels (LABAN's Qualities of Movement)³

- **Improved musculature**

Students display greater strength and stamina in everyday life.

We have observed that each student has gained increased self-esteem, self-confidence and empowerment. And of course the students benefit from this in everyday life.

We started the APA project after having attended the 9th EUFAPA⁴ conference (in Torino Italy in 2008) on sport and movement adapted for people with functional disabilities. We were so inspired by what we saw, experienced and tested that we brought the ideas home to Aalborg where we adapted them to our group of students. At the time we did not feel that the school's physical education programme was sufficiently functional. Typically it consisted in doing exercises recommended by the physiotherapist and we found that all the fun and social elements of sport had been taken out.

Our line of thought was that sport is for all. And this means having to adapt the exercises to each individual student. The exercises must not be too difficult for the students to carry out but on the other hand they must not be too easy either so they do not provide the students with enough of a challenge. If we manage to get the level right, the lessons will give the students some really good experiences of success. Later on we discovered that this is in line with university research in the U.S., which we became aware of when working with Professor Lauren Liebermann of Brockport University in New York⁵. Lauren Liebermann is, among other things, the ideas woman and driving force behind Camp Abilities⁶ and has written several articles on sport, communication and the deafblind.

The student group

During the few years we have been using APA at CDH, we have been teaching five students with deafblindness and nine deaf students with an additional disability. Each group has consisted of six students – two deafblind students and four deaf students with an additional disability.

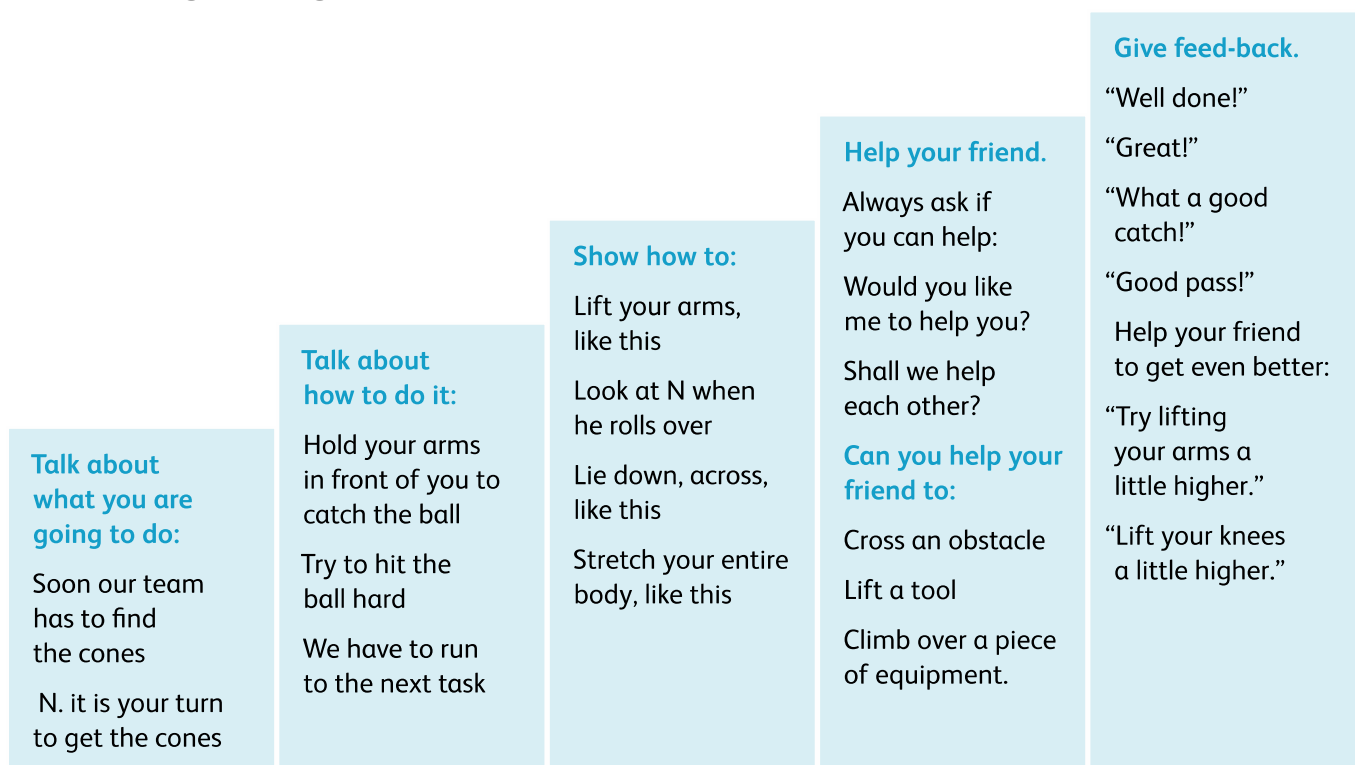
The student groups were put together based on their individual communicative and physical potentials and competences.

Case study: APA unlocked N's potentials

When we started the APA group, one of the students was a shy boy of 12 with CHARGE syndrome (N) who had a low self-esteem, found social relations difficult, did not benefit much from, nor found much pleasure in physical education and was very dependent on his main teacher as his only route of communication with a trusty adult. Through the sporting and social elements, which are the central principles of APA teaching, N developed slowly but surely. He started to expand his routes of communication, interacting with the other students and expressing his activities in words and signs. His self-esteem had increased through experiences of success and thus he gained the energy to help the other students in the group. N felt at ease with the exercises and himself. In the end he took on some sort of leadership role in the group. This made us realize his potential as a positive role model. During the

same period we were introduced to Lene Hammer, the Accessibility Coordinator at the Swedish National Agency for Special Needs Education and Schools⁷ (Specialpedagogiska Skolmyndigheten) who has put the peer tutor concept⁸ into words. Through her presentation and our conversations we felt inspired to test the peer tutor concept on N. We have now been doing this for two years with great success. We see that N grows with the role and gains good competences in selecting information and preparing, presenting and carrying out the lessons – though still with the guidance and support of a teacher. We evaluate each lesson and the result of the evaluation is used in the next lesson.

Steps for guiding friends as a peer tutor



European cooperation: COMENIUS 2011–2013

Danish legislation stipulates that special schools must offer the most recent and relevant teaching methods and didactics⁹. As Denmark is not exactly self-sufficient in this area, it is necessary to cooperate across borders in order to be at the forefront of the development. In the “COMENIUS”¹⁰ project in 2011–2013 we cooperated with the Åsbacka School¹¹ in Gnesta, Sweden and Kentalis Rafaël¹² in Holland on developing APA for the deafblind, focussing on creating a joint catalogue of ideas with exercises for the lessons and on discussing methods and didactics¹³. We visited each other both with and without students and presented our results and experiences at EUCAPA2012 in Ireland.

Apart from participating in the “COMENIUS” project we have also benefitted from participating in EUCAPA’s European conferences every second year. Here we meet

with a wide variety of other professionals – teachers, professors, researchers and other professionals from the academic world. At EUCAPA we are also introduced to the latest methods and research results. Each time there are many relevant presentations and practical workshops which is why we tend to take advantage of the fact that there are two of us with each our own student group; Mads Kopperholdt from the deafblind area and Anders M. Rundh from the hearing loss area. After a long day at the conference we always exchange impressions and notes from the various presentations we have attended individually. Based on the ideas from the conferences we have developed some concrete teaching tools such as: The CDHWALL¹⁴, coupled swings, fitness equipment and a multitrack. In order to carry out our ideas we have cooperated with the universities and colleges in our locality. In that way we have been able to provide our students with a new environment and innovative and exciting teaching methods.

Conclusion

We have now been using APA as an integrated part of our teaching methods at CDH during the last couple of years and with good results. By applying experiences from other schools in other countries and with new innovative teaching methods we have established a niche within sport and movement. This is a niche where the individual is in focus but still interacting with the other students in a group. The strength of this is the group dynamics and the fact that the individual student feels that he or she is being accepted and is actively and socially participating in the group. The fact that the students look up to each other, “do as” and communicate with other students has the effect that the teacher is only a tool who creates the best possible environment for this interaction and then withdraws. The outcome of this is that the students feel joy and a desire to move around and a desire to be with other people who have different levels of function and they look at others as their equals – both during the APA lessons and in everyday life.

Future suggestions

When working with APA we have discovered the importance of evidence-based knowledge. We have also learnt that, in Denmark and probably in the rest of Europe generally, we are not very good at using the universities as collaborative partners in connection with APA. Our experiences from the U.S. have shown us that they have involved their research centres to a larger degree and thus have more documented results. The world is not as big as it used to be and with the possibilities of the internet we would like to prepare the ground for a global cooperation in the field of APA due to the necessity of evidence-based teaching, among other things. As an APA team we would like to get inspiration from other countries and colleagues thus making the most of each other’s strong points. We highly recommend that you attend the EUCAPA 2016¹⁵ and that you come to Aalborg on 5th – 8th September 2017, where CDH will host The European Conference on Deafblindness “Touch of closeness”¹⁶.

Literature for inspiration:

Books:

Lära tillsammans – samarbetsorienterat lärande för ökad delaktighet (Learn together – co-operative learning for increased participation, 2013). Lena Hammer 2013. The Swedish National Agency for Special Needs Education and Schools, Specialpedagogiska Skolmyndigheten (SPSM).

Physical Education and Sports for People with Visual Impairments and Deafblindness: Foundations of Instruction: Lieberman, Ponchillia, & Ponchillia, 2013. AFB PRESS U.S.A.

“Sport is for all” <http://www.eufapa.eu/index.php/component/content/article/31-information-from-countries/128-denmark.html>

With Brain, Hands and Heart: 20 years of Physiotherapy and Education in English in SAMK. www.theseus.fi/handle/10024/85932

Websites:

“Forløbsbeskrivelse: Rehabilitering og undervisning af børn og unge med tidligt konstateret høretab 0–18 år.” (Progress description: Rehabilitation and teaching of children and young people aged between 0–18 with early diagnosed hearing impairment). April 2015. (www.socialstyrelsen.dk); Strategi 2018 (www.rn.dk); The Danish Ministry for Children, Education and Gender Equality (www.emu.dk); www.deaftv.dk; www.handivid.dk

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¹ APA is a practical approach – the key to getting all people with a functional disability to participate in sport or movement together with other people. (www.sportanddev.org/en/.../sport_and_adapted_physical_activity__apa_)

² Center for Deafblindness or Hearing loss, (CDH), Aalborg, is a service for children, young people and adults with either congenital deafblindness or hearing loss (www.dbc.rn.dk.) CDH is a small corporate member of Dbl.

³ http://en.wikipedia.org/wiki/Laban_Movement_Analysis

⁴ European Federation of Adapted Physical Activity. (www.eufapa.eu/index.php/eucapa/history.pdfps).

⁵ www.brockport.edu

⁶ www.campabilities.org. Campabilities is week-long sports camp for children with visual impairments.

⁷ www.government.se/...agencies/the-national-agency-for-special-needs-ed.

⁸ www.council-for-learning-disabilities.org/peer-tutoring-flexible-peer-me...

⁹ “Forløbsbeskrivelse: Rehabilitering og undervisning af børn og unge med tidligt konstateret høretab 0–18 år” (Progress description: Rehabilitation and teaching of children and young people aged between 0–18 with early diagnosed hearing impairment).

¹⁰ The Comenius programme is a European Union educational project. It concerns school-level education, and is part of the EU’s Lifelong Learning Programme 2007–2013.

¹¹ gulasidorna.eniro.se/f/åsbackaskolan:14522472

¹² www.kentalisonderwijs.nl/Rafael/

¹³ <http://cdh.rn.dk/Afdelinger/Hoeretabsomraadet/APA--Adapted-Physical-Activity>

¹⁴ The CDH-WALL is a “box” on wheels which is 2 m X 2.5 m X 40 cm. The box has 24 square light panels on the front and inside, it has an advanced state-of-the-art computer which controls 20 different interactive games centered around the light panels which switches on and off (<https://www.youtube.com/watch?v=5iX5jgL69vE> ; www.eufapa.eu/index.php/home/163-video.html)

Secretariat News

Meetings

In October 2015 the Management Committee (ManCom) met in London to progress the work set out by the Board.

Key activities included:

- Increasing the diversity of the membership and the Board
- Supporting Dbl Networks
- Aligning the budget to the key priorities
- Reviewing the Dbl Constitution
- Developing the 2015–2019 Strategic Plan

Conferences

World Blind Union (WBU) – International Council for Education of People with Visual Impairment (ICEVI) Joint Assemblies, 2016

ICEVI is a partner organisation with Dbl and we encourage you to attend the joint WBU-ICEVI event at the Rosen Centre Hotel, Orlando, Florida, USA from 18–25 August 2016. The Dbl Board and ManCom will be meeting prior to this event, with many remaining to participate in the conference. Registrations can be made at the following website www.icevi.org.

Dbl 9th European Conference, 2017

Start planning for the next Dbl conference in Aalborg, Denmark on 5–8 September 2017. This conference is an amalgamation of the Nordic and Acquired Deafblind Network conferences so is an event not to be missed. Please visit the conference website www.dbi2017denmark.com for the latest information.

9th Helen Keller World Conference, 2018

The World Federation of the Deafblind (WFDB) is holding its next world conference in Spain from 20–28 June 2018. Details are still emerging and when available will be provided.

Dbl 17th World Conference 2019

Take a trip Down Under and visit the Gold Coast, Queensland for the Dbl World Conference in August 2019.

Partnerships

Dbl is in the process of becoming a signatory to the World Federation of the Deafblind (WFDB) and World Association of Sign Language Interpreters (WASLI) Joint Statement of interpreting for people who are deafblind. The existing statement can be reviewed at: <http://wasli.org/wp-content/uploads/2014/01/wfdbmou.pdf>

In December 2015, the Board approved Board members Henriette Hermann Olesen from the Centre for Deafblindness and Hearing Loss, Denmark and Dennis Lolli from Perkins International, USA becoming members of the Dbl Management Committee. Henriette will take up the position of Network Coordinator and will support the Dbl Networks in this important role. Dennis' role will be Diversity Officer, with Dbl recognising the need to increase membership and the Board composition from those countries not well represented, such as Asia, Africa and Eastern Europe. We welcome Henriette and Dennis.

How To Keep Connected

You can keep in touch with colleagues a number of different ways:

Via the Networks on the website:

<http://www.deafblindinternational.org/networks.html>

<https://www.facebook.com/dbiint/>

@DeafblindInt

Old fashioned email: secretariat@deafblindinternational.org

Become a member by contacting us.

Matthew Wittorff & Bronte Pyett

Dbl Secretariat

Proudly hosted by Senses Australia

9th Dbl European Conference, Aalborg Denmark

September 5–8, 2017

Deafblind International, together with The Center for Døvblindhed og Høretab (Centre for Deafblindness and Hearing Loss, CDH), welcomes participants for the 9th Dbl European Conference.

The title of the conference is ***Touch of Closeness –maintaining social connectedness***. The central theme of the conference is social connectedness.

Social connectedness is about how people come together and interact.

The conference program will include plenary sessions, workshops and posters. The Scientific Committee is developing a program that will emphasize interactivity.

The conference venue is the Aalborg Congress and Culture Centre, one of Scandinavia's largest and most flexible congress and culture centres.

Registration opens in September 2016

For more information, check out the conference website:

<http://dbi2017denmark.com/>

European Conference coordinator requests notification of interest in pre-conference sessions

Dbl networks, working groups or any special deafblindness related interest groups wishing to organize a Pre-Conference on Monday, September 04, 2017 contact: Helle Bueland Selling, Dbl European Conference Coordinator, Center for Døvblindhed og Høretab, Email: helle.buelund@rn.dk

The conference venue is the Aalborg Congress and Culture Centre, one of Scandinavia's largest and most flexible congress and culture centres.

Registration opens in September 2016

For more information, check out the conference website:

<http://dbi2017denmark.com/>

WBU-ICEVI Joint Assemblies 2016

18–25 August 2016

Rosen Centre Hotel, Orlando, Florida, USA

ICEVI Day – 22 August 2016

For registration go to: www.wbu-icevi2016.org

Dbl 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, Strategic Planning Officer, Network Coordinator and Diversity Officer.

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Board Observers

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

International Council for Education of People with Visual Impairment
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Website: www.icevi.org

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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, Dbl 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 Dbl Management Committee:

Review of guideline: 12 months after date of endorsement

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