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Review



Dr. Jan van Dijk, 1937–2018

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

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Cover: Dr. Jan van Dijk, 1937-2018

A message from the President

Dear Friends and colleagues,



Since my last report we have had a wonderful European DbI conference. Over 500 delegates

from 30+ countries attended the fantastic venue in Aalborg. DbI holds its business meetings to coincide with these type of events, so we had our Management Committee, Board meeting and AGM in the two days preceding the conference.

We recognised the work of people who are leaving 'our field' through retirement or simply moving on, but so often individuals stay with us continuing their DbI work and interests irrespective of their national organisation interests. Huge thanks to each and everyone of you.

Delegates at the conference ranged from individuals from Malawi and Ethiopia really doing remarkable work alone and in often difficult circumstances to 14+ people from Russia. Other countries attending included Netherlands, Catalonia, America, Canada, Croatia, Latin America, Scandinavia, Spain, Italy, Austria, Argentina, Norway, Sweden and so many more. Apologies if you are not mentioned.

There were a number of pre-conference events including the Nordic, Usher and Youth networks. After the conference the Outdoor Network had a wonderful week bringing

staff and deafblind people together 'experiencing the great outdoors'.

Around 30 delegates attended the Usher network preconference, with everyone reporting how helpful it had been; sadly the running theme throughout was 'the lack of funding'. There was also a very successful CHARGE pre-conference with well-known speakers including David Brown.

One of the most important aspects of the conference was the theme of inclusion. Most of the major sessions had people with deafblindness chairing or presenting.

It was great to welcome the new Adaptive Physical Activity network who also contributed hugely to a range of wonderful volunteers who did a fantastic job over the conference week.

DbI itself has three key priorities, diversity, technology and knowledge through our conferences and networks. The connections we have made in some of the African nations remind of us how important it is to focus on diversity. It is so important because we miss the 'richness' other countries bring to our work and of course those countries with more developed deafblind programmes have a responsibility to support and share practice.

The University of Addis Ababa, Ethiopia has published the first ever 'Baseline Survey Report on the State of Deafblindness in Ethiopia'. Aside from useful statistics on prevalence, for the first

time the report describes age, gender and condition of a small number of people with deafblindness in the country.

I think we are increasingly getting better at knowledge and sharing practice but obviously we can always improve and of course the 'application' of knowledge is key. Where I think the conference and indeed all of us feel we struggle still seems to be in technology. There are some amazing developments but often they are driven by one or two key people and stop at the point where a personalised solution has been found.

I visited the Russian Deaf-Blind Support Foundation Connection in June. We are all pleased that Dmitry's team supported the publication of the History of Education of Deafblindness in Russia. I am also privileged to be a Trustee of Connection and look forward to developing our work together.

The ManCom is delighted to note the continuing development of the America's conference planned for April 2018 where DbI hope to join the event with our next Management Committee meeting.

As ever our huge thanks must go to Stan and CDBA for the wonderful work on this DbI Review; to Able Australia and Gary for the massive amount of Secretariat work and of course to Frank and Kentalis who always go 'above and beyond'. Our deafblind community is important and thanks to everyone for your continued support; so much appreciated.

With Best Wishes
Gill Morbey, DbIPresident

Editorial

Welcome to the 60th Edition of DbI Review.

As an international organization, Deafblind International has always recognized diversity as an integral part of its mandate, without having specified this as a strategic priority until recently. With the adoption of its new Strategic Plan, DbI is excited to pursue and expand this initiative. DbI Review has been in the past and will continue to be an avenue to highlight diversity-related activities which promote the identification and development of services for individuals with deafblindness from all corners of the world.

This edition opens with an article prepared by Graciela Ferioli and Dennis Lolli titled: 'Diversity: Deafblind International's Strategic Plan Moves Forward'. It explains DbI's actions to support its diversity focus, and includes supporting comments from prominent diversity proponents in the deafblindness field.

Another article with a diversity approach features Pilar Barragan Cristancho, an actress from Colombia who is deafblind. According to Pilar, "we are able to show the public through this theater situation the many things that they did not know about who we are as persons with deafblindness, how we live, what we do, how we think, our different communication abilities and capacities to communicate while dealing with difficult situations, while showing our good sense of humor and love for our family and our children".

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Vice Presidents' Messages

Bernadette M. Kappen reports:

Energy and excitement are two words that describe DbI. The European Conference in Aalborg focused on the importance of touch and gave all the participants a deeper understanding. The presentations and personal experiences shared by individuals related to touch were the highlight of the conference. Excitement was evident every day in the sessions and seen during the breaks and social activities.

DbI is working to connect people around the world and we want to reach out to professionals, families and consumers who are not able to attend conferences.

The development of the new DbI website has these connections as the main goal. In Aalborg we had the opportunity to meet with participants from different countries to discuss the website. The energy and excitement from the individuals who attended this meeting helped shape the new website. DbI is now active on Facebook and Twitter to keep people connected throughout the year. The goal is to promote awareness and to assist people needing information to support individuals who are deafblind.

The next event for DbI is the Network of the Americas Conference



in Hyannis, MA, USA. This is the time for us also to honor individuals with the DbI Awards. Please consider nominating individuals for the Young Professional Leaders Award, the Distinguished Service Award and the Lifetime Achievement Award. Information about the awards is on the DbI website and in the DbI Review.

Bernadette M. Kappen
(bkappen@nyise.org)

Frank Kat reports:

Now that we are roughly halfway through the 2015–19 term of the current Board and Management Committee, it is a good time to pause and think about how we are doing. Most importantly, we are well on our way to achieving our ambitions, as evidenced by the results that we shared during our meetings in Denmark. What a wonderful conference that was!

My task has been to focus on Social Media and Technology. Never before have we been this visible in the media. Our website has undergone a complete make-over and is now great to browse on a smartphone. Graciela Ferioli was the driving force behind this. There are no longer any large sections of text, and there are more images and outlines. I am also very proud that there is now room for stories, too. For instance, the blog by Femke Krijger. Femke is the first to share her experience and vision under the beautiful title:

Touch of Closeness (<http://www.deafblindinternational.com/touch-of-closeness/>). If you would like to share your experiences, events or stories, please contact us. I should like to invite you to follow DbI on Twitter or to 'friend' us on Facebook. This is, after all, a beautiful way of connecting the DbI 'family'.

I also participated in the ATAD First International Conference on Assistive Technology and Disabilities. It provided clear insight into ongoing research in relation to technological trends for people with multiple sensory challenges. Developments that offer support in deafblind people's lives, for instance aimed at more independence and autonomy, are advancing extremely quickly. There is already so much available now, but there is also a great deal of work to be done. When such technology is made use of, it is essential, from a practical point of view, to set it up together with the users.



We have also made considerable progress on the other two core objectives (Diversity and Networks), which this edition will inform you about. Deafblind International is financially healthy. In the coming two years we will therefore invest additional means in the three core objectives. We can afford to under the current circumstances. We are also looking for new members to strengthen our work and organization.

I can look back on an active year with much satisfaction. Let's go and open new doors together.

Frank Kat (F.Kat@kentalis.nl)

Diversity: Deafblind International's Strategic Plan Moves Forward

Deafblind International (DbI) is in the process of addressing diversity as a major priority. Our Strategic Plan directs us to create a climate of diversity throughout all aspects of our operation. To accomplish this, we are taking steps to become a more inclusive organization that is accessible to individuals from various cultures, geographies, socio-economic backgrounds, with different languages and having a range of functional abilities.

Through working in a sustained way for more than 40 years, DbI has learned that it's time to become an organization that embraces a more inclusive membership and practices which reflect the diverse world in which we work. To begin, we are initiating a greater exchange through social media using different languages and publishing articles from a wider range of countries. Together with facilitating conferences hosted in different regions of the world, DbI will be offering a broader global reality. By embracing a more cultural and linguistic diversity we believe that DbI will deepen its organization strength, broaden its vision and provide members with greater and more meaningful opportunities.

Going further as an organization, we continue to strive to have diversity become part of our consciousness and professional activities. Deafblind International will continue to be cognizant to have diversity reflected in both its mission and practice.

To move this process forward, the Management Committee and the Board voted to support efforts to achieve our diversity goals through:

- Encouraging access to membership for colleagues from underrepresented regions, particularly Asia and Africa.
- Having conferences reflect increased diversity through programming, participation and outcomes.
- Sponsoring within budget capacity, individuals who reflect diversity to participate at meetings and events.
- Working for future conferences to be located in regions/areas that make it easier for diverse populations to participate.
- Exploring how to increase participation at Board Meetings by individuals who can reflect the needs and situations of more diverse regions.
- Having an increased number of DbI materials and articles translated into other languages.

Actions approved to accomplish these objectives:

- DbI will have diversity as a factor when selecting locations for meetings and conferences. It has been announced that the 2021 'regional' conference will be held in Africa. We have early expressions of interest from Malawi and Ghana
- DbI will ensure that conferences bearing the DbI logo will have their programs address topics reflective of such diverse needs as: poverty, limited access to centralized services, prenatal and early childhood health issues and native populations, just to mention a few.
- DbI intends to expand its activity in Social Media, using the platforms of its website, Facebook and Twitter. With its wide global accessibility, social media will become a more routine way for DbI to share information regarding meetings and local activities. For example, in the video link as follows we are sharing activities developed by different programs, announcements from the United Nations:
<http://educationcommission.us12.listmanage2.com/track/click?u=ae75450d327bd33f02ee8824a&id=f1e8f4657e&e=e2ad5a920e>

“Our Strategic Plan directs us to create a climate of diversity throughout all aspects of our operation.”

- In early October 2017, we launched a reorganized DbI website. It is intended that this dynamic new site will be maintained with regular updates to keep it relevant and current. With the changes, the DbI website is also now more user friendly and easier to navigate. While the website will continue to provide information on such key DbI activities as Membership,

Conferences/Meetings, Networks and Publications, it will eventually include an Audio Visual Library to provide all types of media resources including options for webcasts and live streaming.

- At our recent DbI European Conference in Aalborg, Denmark, a strong example of diversity was evident in the widespread

collaboration of DbI members with an exceptionally large number of European and non-European countries. Of particular interest was the opening Conference message from Mrs. Mai Mercado, Danish Minister for Children and Social Affairs, which was translated and subtitled in English, Italian, French, Spanish and Portuguese.

COMMENTS FROM VARIOUS CONFERENCE ATTENDEES RELATING TO DIVERSITY



Students studying at an inclusive school in India

Sampada Shevade, India

In recent years the population of students with deafblindness has grown more diverse, and teachers have struggled to gain knowledge and modify teaching approaches to teach these students.

To ensure that all children with deafblindness have access to quality education, education policies and practices must be inclusive for all learners, encourage the full participation of all, and promote diversity as a resource, rather than as an obstacle. It is also important to look at education not

only as a tool that facilitates academic learning, but most importantly to facilitate learning to live in a social world – a world with diversity.

To be able to equip ourselves with the recent approaches and trends, we have to not only teach but also need to learn and share good practices. It is about time we learn to recognize, respect and accept diversity.

“The problem is not how to wipe out all differences, but how to unite with all differences intact.”

–Rabindranath Tagore

Nikolina Juric, Croatia

The history of DbI entails growth resulting from working and sharing ideas together. I support the initiative to bring the climate of diversity to all aspects of DbI, which seems a natural step for such an organization. I studied in the Perkins Educational Leadership Program in 2015/16, and work as a

member of a best practice program: Malidom¹, in Zagreb, Croatia. I have had more access to resources and education than some of my ELP colleagues, but I didn't have their experiences. I believe I managed to convey my admiration for the work my ELP² colleagues do in their countries. I have learned

that we all can benefit from sharing ideas and hearing some very creative ways to work with Deafblind students as well as means to influence local government. Also, applying the idea of diversity in the social media platforms can be liberating for the not-so-visible cultures. I can imagine that finding

¹ www.malidom.com

² ELP – Educational Leadership Program, Perkins School for the Blind (www.Perkins.org)

information (in your own language) about parents who are going through the same process as you and are successful, can be influential. So, for a parent, a teacher or even an elementary school student writing a paper or gathering information about deafblindness trends and practices, this accessible format and social media presence would be of great benefit.



This photo shows a first field trip for a young boy (in striped t-shirt) and his proud mother. The family moved to Zagreb from a neighboring country to access services from our program

CIDEVI Institute, Chile³

The education of students who are deafblind requires well trained professionals as well as ongoing support offered to families. To achieve this, it is essential that schools and organizations have a strong history, good work experience and are dedicated to lead and support others in our field. It is also important that these organizations acquire visibility with neighboring countries and other continents.

Based on the experience we gained by working in South America, we know for sure that the opportunity for working in teams and sharing knowledge has definitely

enriched our educational work. This has also brought hope for the families, by letting them know that they are not alone. Sharing experiences and maintaining contact has certainly contributed to the internal work of each country in the region.

The use of social media facilitates communication and a tool that allows for a collaborative learning process while at the same time creates a place for sharing information and promoting cooperation among organizations, countries and continents.

The contribution Deafblind International is making

by sharing what is globally happening in the field is of great support. It helps the growth and development of each institution and the building of relationships among persons, families, professionals and communities.



Ksenia Smertina, Deaf-blind Support Foundation "Con-nection", Russia⁴

Re: DbI's Global Diversity Initiative:

The contribution to this initiative for "Con-nection", is through establishing strong ties with the international community through establishing close cooperation with all our partners, including members of DbI.

For this reason, we are now launching an exchange program with Perkins School for Deafblind. We have already completed a Summer School Program together with specialists from Royal Dutch Kentalis and hope to proceed further in such a way in the future. We are also in close cooperation with Sense

International leadership discussing our common goals and future projects.

The crucial thing for Russia is to make our deafblindness school a model that the international community can learn from. To achieve this, we have released a book by the prominent Russian expert, Tatiana Basilova, titled: 'The

³ <http://cidevi.cl/w/>

⁴ www.so-edininie.org is a small corporate member of DbI



Pottery class for deafblind child in Russian Resource Center "Yaseneva Poliana"

history of Russian Deafblind education' (in English)⁵.

As well we eagerly contribute to each edition of DbI Review. We also are thinking about making the DbI material more available for every professional in Russia. For this reason, we are taking such effort to translate each edition of DbI Review into the Russian language, calling it DbI Review Russia. A special feature of the

Russian edition is that we include materials from national authors to inform our Russian readers about our own development. As well we usually include information about the growing number of events organized by our Foundation or by our partners. In the future, we hope to contribute more to this initiative through research projects with Russian experts.

From Knut Johansen, Norway

One good thing about diversity is that it includes anything and everything, anyone and everyone. Diversity has very different aspects. The first thing that comes to mind is geographical diversity. Of course, this is important for an international association. Equally important, however, is diversity in a broad range of other areas. We should bear that in mind. The diversity in the way

individuals with congenital deafblindness express their thoughts, wishes and desires enriches our understanding of what communication is. For DbI this also includes diversity when it comes to working with individuals who have congenital or acquired deafblindness; working with children, youngsters or adults, if you are a teacher, a social worker, a researcher, a parent, a sibling or another family

member, administrator etc. It also includes diversity in gender and age. It includes different approaches in our work, based on local traditions, human resources, know how and financial support. All taken into consideration, diversity is the only way to think and act when we try to succeed in including everyone, and is the ultimate way of enriching our common purpose.

Moving forward toward a more diverse, mature and active organization, we invite you to offer comments and thoughts to us about this article and DbI's exciting direction. So, in closing, we are asking that you feel comfortable in sharing your questions and/or suggestions about this article.

- What other aspects of diversity should we include? What are other diversities that we need to consider?
- What other ideas came to you through this article?

We further invite you to share your good practice so they may become part of our website and facebook announcements. Remembering the words from Frank Kat in Aalborg: *"Our future is about strengthening partnerships: in our field, with disability groups and with organizations."*

**Kindly send your feedback to either
Graciela Ferioli (g_ferioli2000@yahoo.com.ar
or Dennis Lolli (dennis.lolli@perkins.org)**

⁵ <https://www.jpc.de/...history-of-deafblind-education-in-russia/.../77...> -

From Deafblindness to the Theater

Pilar Barragan Cristancho, Deafblind Leader in Colombia

Today I quote Ricardo Arjona's¹ song, that said: "Who would say that deafblindness and theater could go together?" I thought this was impossible before, but thanks to Rodrigo González, a young theater director who believed in our abilities, a performance called "ConSentidos" was presented in Bogota, Colombia, during four consecutive weekends in September 2017.



Pilar Barragan Cristancho

For those of us deafblind actors on stage acting in different scenes, it was an experience that made a deep imprint on all of our own lives. We represented characters we remembered from our own past as well as our present. This helped us to put all our feelings and our heart into this play, which couldn't be compared to anything else.

My stage partners, Ruby, Jose Richard, Pedro, David and I, faced one of the greatest challenge of our lives. Each of us has experienced difficult moments in our life, which allowed us, as deafblind

persons, to now communicate about how we live, feel and experience everything that occurs around us.

Through this theater situation, we were able to show the public many things that they did not know about who we are as persons with deafblindness, including how we live, what we do, how we think. We were able to show our different communication abilities, our different capacities to communicate while dealing with difficult situations, as well as showing our good sense of humor and love for our family and our children.

With theater, we were able to demonstrate that not being able to see or hear was not a problem – but it was a challenge. Initially the performance was difficult. But through everyone's effort and dedication, supported by the patience of our director and guide interpreters, we worked with enthusiasm through each situation. Before going on stage, all they could do now was wish us luck with a big hug, because otherwise, we had to do it ourselves.

I never thought that after twenty-one years with acquired deafblindness, that I could remember those questions that came to me when I had my first baby, when I was unable to see or hear him. I had to face again the fear that I had experienced many years ago about the fact that my son wouldn't have a mother like other children.

But today I can say with satisfaction and pride that as persons with deafblindness, I have been able to face and

“We represented characters we remembered from our own past as well as our present. This helped us to put all our feelings and our heart into this play, which couldn't be compared to anything else.”

¹ https://en.wikipedia.org/wiki/Ricardo_Arjona



overcome all the barriers that seemed to have prevented me from having a happy life. I realize now that I have a beautiful family and enjoy the incredible love of my husband and children who are proud of their mother with deafblindness.

And with this same love we hoped to reach many more people in the audience, to tell and demonstrate to them through the theater experience that not all is lost for us! That God will

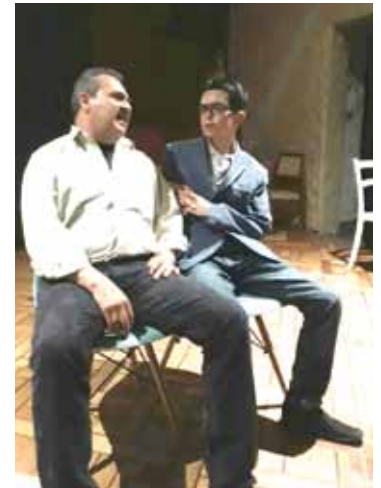
“In all our memories will be the happiness of our feeling the vibrations of the floor made by the excited tapping of the audience, and the spontaneous way they approached us at the end of each performance.”



always help us provide the means through which we can enjoy our lives. That if we have difficulties, we will have the security of having the strength to overcome them, and as a friend says, “to have an appointment with the sun”.

I know it will remain in the memory of those people who saw us act: the beautiful smile of Ruby; Jose Richard’s tenderness; Pedro being an example of a good father; David’s jokes and the strength that God has given me the go ahead in life.

In all our memories will be the happiness of our feeling the vibrations of the floor made by the excited tapping of the audience, and the spontaneous way they approached us at the end of each performance. This will always be remembered. This has filled all of us with the wonderful thrill that assured us that the audience had really understood our message.



Not only did those of us as actors with deafblindness enjoy the happiness of being able to make deafblindness and theater a success; but also for our families to discover our new talents as actors through this pioneering project in Colombia.

We dream of carrying our message to other cities and countries. Just as we had the support that made possible our dream in Bogota, we hope that many more will join us to make more persons with deafblindness discover that there is an outside world full of possibilities.

We want those who can see and hear know that there is capacity in those of us with a disability; that even without seeing or hearing, it is possible “to see the light at the end of the tunnel”.

EDITOR'S MESSAGE *(continued from page 3)*

Continuing on this theme of diversity, an article from Sense International India, prepared by Atul Jaiswal, Uttam Kumar and Akhil Paul, suggests that persons with deafblindness are generally invisible within the scientific literature. This lack of research from India and the countries of South Asia, pose significant challenges to this unique population, including missed diagnoses, limited access to appropriate services and nonrecognition in society.

The inclusion in this edition of a report received from one of DbI's partner organizations, the World Federation of the Deafblind, further highlights the barriers that persons with deafblindness face. These include lack of access to support services, accessible information and assistive devices which make it difficult for these individuals to support themselves to voice their issues. WFDB (and others) have shown that there is very little attention paid by National and International stakeholders on the issues of persons with deafblindness. This is both the result and the cause of the general lack of knowledge of the diversity of issues and specific inclusion requirements of persons with acquired or congenital deafblindness.

To further highlight 'diversity' in this issue, Sonia Margarita Villacrés Mejía from Ecuador has penned an article describing the development of WFDB. Sonia Margarita had a significant role in the development of this organization; she was a former President and continues to have a prominent role.

While the articles mentioned above focus on diversity, no one can dispute that the recent DbI European Conference held in Denmark was a prime example of an incredibly diverse activity organized by DbI. Attendees from 30+ countries came to Aalborg, September 05–08 to attend the conference titled: 'Touch of Closeness – Maintaining Social Connectedness'. The article prepared by the editor titled: 'Highlights of the 9th DbI European Conference' summarizes the transcripts from the conference. Over 500 participants from 30+ countries were represented in Aalborg, of which twelve of the countries were from outside North America, Western Europe and Australia.

Two other notable feature articles are included in this edition: 'Conducting psychotherapy with individuals with acquired

deafblindness' and the sixth and last in series of Action Research in Deafblindness articles. The purpose of this excellent research series was to provide information to support practitioners in the field of deafblindness to conduct research.

In closing, this edition follows a similar framework of including articles from various Networks, providing details on upcoming conferences and featuring country-specific articles placed in the Country News section. Once again colleagues from the Russian Organization Connection are to be congratulated for more of their interesting and colourful articles.

In closing, I wish to extend my deep thanks once again to the many collaborators who submit articles to support this valuable publication.

**Respectively,
Stan Munroe, January 2018**



HIGHLIGHTS OF THE 9TH DbI EUROPEAN CONFERENCE

‘Touch of Closeness – Maintaining Social Connectedness’ Aalborg, Denmark, September 05–08, 2017

Over 500 participants from 30+ countries attended the 9th DbI European Conference in Aalborg, Denmark, September 05–08, 2017. The conference was ably hosted by the Centre for Deafblindness and Hearing Loss¹ which provides a nationwide program for children with acquired deafblindness, persons with congenital deafblindness and people with hearing loss in Denmark.



Touch of closeness
maintaining social connectedness

The Conference got underway in the evening of September 04 with a warm welcome from Thomas Kastrup-Larsen, the Mayor of Aalborg, followed by a welcome reception at the Kunsten Museum of Modern Art².

DAY 1

September 05, 2017: THE OPENING SESSION

The official opening on September 05, featured welcome presentations from Lars Soby (Chair, Local Planning Committee³), Gill Morbey, (President of DbI), Jude Nicholas (Chair, Scientific Committee⁴), and Ulla Astman, (Chairperson for the Council of The North Denmark Region). In his welcoming address, **Conference Chair Lars Soby** suggested that this was indeed an international conference not just a regional one. It is impressive to witness such a strong commitment by individuals working in the field of deafblindness to come together from such wide distances to share their knowledge and join

professional networks to enhance their personal development to enhance their support for people with deafblindness.

The conference theme, Touch of Closeness maintaining social connectedness lead us to remember one of the most essential issues of human life is our on-going need to connect and interact with each other in social relations. Being in a close meaningful and positive relationship is crucial for any person’s development and wellbeing and ensures that our lives are meaningful and enjoyable. Deafblindness challenges this encounter. When lacking a significant amount of both hearing and sight, people

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

² kunsten.dk/en

³ Members of the Local Planning Committee: Lars Ejsing Søbye (Denmark), Maria Creutz (Sweden), Else Marie Jensen (Denmark), Trine Skov Uldall (Denmark) and Helle Buelund Selling (Denmark)

⁴ Members of the Scientific Committee: Jude Nicholas (Chair-Norway), Henriette Hermann Olesen (Denmark), Else Marie Jensen (Denmark), Kari Schøll Brede (Norway), Stefan Wiik (Sweden), Liz Duncan (England), Trees Van Nunen (Netherlands), Nadja Högner (Germany) and Linda Eriksson (Sweden)



Conference Chair Lars Sobje



DbI President Gill Morbey

with deafblindness are dependent upon touch to improve and maintain a close relationship, social connectedness and to reduce social isolation. This is the Touch of Closeness.

Lars encouraged the participants to use the different platforms offered by the conference to share knowledge and learn from each other, and wished everyone a very good conference.

In her welcoming address, **DbI President Gill Morbey** indicated how delighted she was to be back in Aalborg to re-acquaint with colleagues in Denmark and the Nordic countries. She also indicated her delight about the theme Touch of Closeness and social connectedness.

Gill indicated it was such an important time to come to this conference, pointing out some perilous issues facing the field of disabilities today. For example, in the UK funding for social care is diminishing, with staff at SENSE⁵ experiencing reductions in funding for their work. She also reflected on concerns she has heard from the World Federation of the Deafblind (WFDB)⁶ about some systemic violations of the human rights of persons with disabilities being

witnessed. She touched briefly on concern about the questioning of vaccinations in some economically advanced countries, as well as continued prevalence of children with congenital rubella syndrome in such countries as India.

Gill also took the opportunity to say that the theme of the conference, touch of closeness, is very special. The sense of connection is a human condition; we all need that connection, whatever our abilities, whatever our interests are. I hope as long as we stay close and connected, while we can't change the world and the external environment that we operate in, we can continue to change the little bit of the world and practice that we have responsibility for.

Chairperson for the Council of The North Denmark Region Ulla Astman welcomed the participants from all over the world emphasising the strength of this special community coming from across the globe in support of individuals who are deafblind. She indicated that The North Denmark Region runs the Centre for Deafblindness and Hearing Loss, the organizers of this conference. Through the past 50 years the Centre has gained extensive knowledge on

deafblindness with staff providing counselling to individuals who are deafblind, their families and to professionals nationwide. To ensure the rights of persons with deafblindness, it is important that we continue to allocate resources to support this service and to ensure the expertise on the area. We are very proud of this in The North Denmark Region.

Furthermore, she suggested that no matter who we are, we all need social contact and we all need fellowship with others; for individuals with deafblindness, touch and contact are crucial for maintaining their social connectedness. She is pleased that the topic of this conference is Touch of Closeness maintaining social connectedness. Due to their double loss of senses, deafblind persons have a particular need to support their social contact and fellowship with others. By supporting and developing their communication skills, they can maintain their social relations and avoid social isolation. To ensure the right effort is provided for these individuals in the future, it is essential that we continue to improve our practice. We improve practice when we share knowledge across borders. When these four

⁵ SENSE (www.sense.org.uk) is a large corporate member of DbI

⁶ WFDB(www.wfdb.eu) is a partner organization of DbI

days are at an end I hope that you all have gathered a lot of new knowledge, inspiration and new contacts, so that we can take on the task together and ensure the best results for people with deafblindness. It is your expertise that makes a difference every single day!

As the final welcoming speaker, **Jude Nicholas, Chair of Conference Scientific Committee**, assured the audience that the committee had planned an inspiring and stimulating program to satisfy the conference theme, which would include various key note and plenary lectures, 45 workshops, 16 poster presentations and a research symposium. The intention was that all the presentations would reflect an exciting interaction of personal perspectives and real-life experiences in the field of congenital and acquired deafblindness.

DAY 1 PLENARIES

SOCIAL CONNECTEDNESS

Two plenary sessions were featured on **day one** with the themes: Isolation according to social connectiveness – the general human aspect and Social connectiveness from the perspective of Technology, Identity and Communication.

The **first keynote** featured Richard Hawkes, Chief Executive of the British Asian Trust⁷. Richard has considerable experience in the disability field including deafblindness. His presentation was titled: 'The isolation of disabled people – global comparisons and issues'.

Richard's paper focussed on his dispelling and correspondingly proposing resolutions to what he

considers as myths connected with individuals with disabilities. First, he argues that it is not automatically the case that disabled people in poor countries are more isolated than those in rich countries. In these situations, individuals innovate and use scarce resources more effectively. Secondly, he suggested that in any society, those disabled people who are rather independent have the strongest personal relationships and sense of connectedness. Whereas those who are highly dependent are the most isolated as their lives are controlled by others. For disabled people to be truly equal in society, attitudes and behaviours of everybody else in society must change. History has shown how difficult it is for societies to accept that disabled people are full and equal citizens, having the same rights to independence as everybody else. This leaves many disabled people in many countries not truly independent, with their lives often controlled by others, in some cases for genuinely good reasons.

The failure to achieve these full rights for these individuals fall at the feet (in some cases) to: parents, professionals in not-for-profit and volunteer agencies and the state. While recognising the rights of disabled people are absolutely crucial, Richard argued that the most important need is for society to change its attitudes towards empowering disabled people to ensure they are recognized as equals in society.

The **second keynote** was presented by Niels Henrik Moller Hansen, Associate Professor from the Danish Centre for Youth Research, University of Aalborg⁸ and titled: *Isolation According to Social Connectedness – The General Human Aspect*.

Professor Hansen, who is deafblind himself, spoke about the rapidly changing social conditions of modern society that persons with disabilities, and in particular those with deafblindness, are living. A few extracts from his paper:

- Our identity is not only based on our own understandings, but also our interpretation of how others view us, together with our actions and interactions with others.
- The responsibility for defining one's identity is open. It is no longer given or dictated by tradition. There is that search for places/communities in which to identify with.
- The responsibility for defining oneself and making life choices is up to the individual person. Things are changing so it is hard to decide what is good or not.
- There is always that search for perfection, with constant pressure for maximize top performance. Failure to give best performance is seen as a personal problem.

Living with deafblindness does not restrict the person; anything is possible but being deafblind is individually defined and left to each person to cope.

The challenges of social connectedness today are that it is hard to be somebody if you don't experience being part of something! Failure is always in our minds. We run faster than ever, yet the goalposts keep escaping us and the responsibility is always our own. Stress, depression and other 'mental' problems are on the rise for us.

Modern society is both a possibility and a risk for people with disability. We must insist that disability is a shared condition and the response must be shared as well. We must strive to educate both society and deafblind people of the realities of living with a disability

⁷ <https://www.britishasiantrust.org>

⁸ vbn.aau.dk

The second plenary session of Day One featured a series of personal stories from four individuals with deafblindness who outlined their different experiences in social connectedness.

- **Scott Davert** (Helen Keller National Centre – USA⁹) shared his extensive experiences with a wide range of technology. Scott emphasized that people with deafblindness can be creative through the wide amount of technology available to meet their needs; the possibilities are endless!
- **Torbjörn Svensson** (Sweden) spoke about how his independent working life as a truck driver was significantly altered with his late onset of Usher Syndrome. He spoke about his loss of independence and isolation resulting from his disability. Thanks to the availability of interpreters to help him deal with his isolation, Torbjörn now feels involved in everything that happens and feels he is no longer outside of the conversations. He can choose to follow what he wants to follow and at the same time knows what exactly is being said around him.
- **Rasmus Munk Pedersen** from Denmark, who lives at the Youth Residence for Persons with Deafblindness in Aalborg, carried on a three-way conversation (on film) with two educators from the Centre for Deafblindness and Hearing loss in Aalborg.
- **Machteld Cossee**, a private citizen from the Netherlands spoke about her personal story, highlighting how the progress of Usher Syndrome affected her home life, working life, sporting life and communication ability. A documentary film was produced about her life and how she and her family deals with her Usher Syndrome. The film was shown after the end of the conference session.

THE WORKSHOPS

September 05, 2017

- **Deafblindness – Theory-of-mind, cognitive functioning and social network in Alström syndrome**
Presenter: Hans-Erik Frölander; Co-presenters: Claes Möller & Björn Lyxell (The National Agency for Special Needs Education and Schools, Sweden)
- **Meaningful rehabilitation for people with acquired deafblindness.**
Presenter: Kirsten Washuus; Co-presenter: Else Marie Jensen (CFD, Denmark)
- **My Journey to Independence: From Isolation to participation (Australia)**
Presenter: Linda Fistonich; Co-presenter: Karen Wickham (Senses Australia)
- **Camp Abilities: educational sports camps for children with sensory impairments**
Presenter: Lauren Lieberman; Co-presenter: Pam Haibach; (The College at Brockport, State University of New York, USA)
- **Never say never! Optimizing senses and functions releases new learning**
Presenter: Line Hovland, Eikholt National Center for the Deafblind, Norway
- **Adapted Physical Activity: from idea to reality – Unlocking potentials**
Presenter: Mads Kopperholdt; Co-presenter: Anders Martin Rundh (Centre for Deafblindness and Hearing Loss (CDH), Denmark)
- **Dreaming about an accessible life**
Presenter: Eric van Heuvelen; Co-presenter: Ilse Oosterhuis (Bartimeus Institute for the visually impaired, The Netherlands)
- **When a party makes sense**
Presenter: Louise Søndergaard; Co-presenter: Martin Hedegaard (Centre for Deafblindness and Hearing Loss (CDH), Denmark)
- **Threepart conversation – A multidisciplinary project**
Presenter: Camilla Lolk Rønshøj; Co-presenters: Tine Nørgaard Pedersen, Helle Buelund Selling (Centre for Deafblindness and Hearing Loss (CDH))
- **To live with PHARC – a novel complex syndrome causing acquired deafblindness**
Presenter: Ane Marte Halkjelsvik; Co-presenter: Inger Marie Storaas (Statped, Norway)
- **Friends from the wild: Developing relationships through ongoing outdoor activities**
Presenter: Joseph Gibson (Deafblind Outdoors, Norway); Co-presenters: Sofia Kristoffersen Nystuen (Norway) and Sunniva Joten Langsjøvdold (Norway)
- **CHARGE and working on social connectedness – a big challenge**
Presenter: Tanja Geck; Co-presenter: Sandra Runge-Fleischer, (Deutsches Taubblindenwerk, Germany)
- **Fun Chi: Adapting Tai Chi for Self-Regulation and Relaxation**
Presenter: Sharon Barrey Grassick (School of Special Educational Needs, Australia)
- **Acquired Deafblindness in Ethiopia and its Coping strategy: The Case of Three Women with Acquired Deafblindness**
Presenter: Dr. Sewalem Tsega (Addis Ababa University, Disability Center and SNE Department, Ethiopia)

⁹ <https://www.helenkeller.org>

THE POSTER SESSIONS

September 05–06, 2017

- **Aspects of learning in deafblindness – opportunities and limitations for persons with Alström syndrome**
Presenter: Berit Rönnåsen (Specialpedagogiska skolmyndigheten, Sweden); Co-presenters: Kerstin Möller (1 & 2), Claes Möller (1,2 & 3), Björn Lyxell (3) and Agneta Anderzen-Carlsson (1 & 2)
School of Health and Medical Sciences, Örebro University, the Swedish Institute for Disability Research, Linköping, Sweden
Audiological Research Centre, Örebro University Hospital
Department of Behavioural Science and Learning, Linköping University
- **Developing social connectedness through physical activities**
Presenter: Anders Martin Rundh (Centre for Deafblindness and Hearing Loss (CDH), Denmark); Co-presenters: Mads Kopperholdt (Centre for Deafblindness and Hearing Loss), Marijke Bolwerk (Royal Dutch Kentalis St. Michielsgestel) & Lotte van de Weem (Royal Dutch Kentalis St. Michielsgestel)
- **Early Steps for Speech Development in Congenital Multi Sensory Impairment**
Presenter: Eva Magdalena Oprea (Cristal, School Centre for Inclusive Education, Romania)
- **Deafblindness connecting people on Facebook**
Presenter: Marcia Noronha de Mello; Co-presenter: Bianca Della Líbera (Instituto Benjamin Constant, Brazil)
- **Implementing Social Haptic Communication in the Netherlands. Partnership in development and training**
Presenter: Marga Martens (Royal Dutch Kentalis, The Netherlands)
- **Water Motion as a platform for Intensive Interaction**
Presenter: Nikolina Juric Tanfara (Special Education Teacher, Croatia)
- **Perceptions of social networks by adults who are deafblind**
Presenter: Katrina Arndt; Co-presenter: Dr. Amy Parker (St. John Fisher College, USA)
- **Health care consumption in infants with CHARGE syndrome – a case-study**
Presenter: Agneta Anderzén Carlsson (Audiological Research Centre, Örebro University Hospital and SIDR at Örebro University, Sweden)
- **Towards common ground: supporting social connectedness through self-regulation**
Presenter: Gro-Anita Tunes; Co-presenter: Evabritt Andreassen (Statped, Norway)
- **Applying Social Impact Assessment methodology at Lega del Filo d’Oro**
Presenter: Patrizia Ceccarani (Lega del Filo d’Oro & Onlus, Italy); Co-presenters: Vurro C. & Romito S. (Department of Management & Technology, Università Commerciale “L. Bocconi”, Milano, Italy)
- **Can work promote social connectedness and better health?**
Presenter: Mattias Ehn (Audiological Research Center, Örebro University, Sweden)
- **The Power of Volunteers**
Presenter: Anya Rakoczi; Co-presenter: Sian Stamper (Sense, United Kingdom)
- **Identified Needs in Deaf-Blindness: Recommendations for Orientation & Mobility Training**
Presenter: Tara Brown-Ogilvie, National Leadership Consortium in Sensory Disabilities (NLCSO) – Fellow; Co-presenter: Silvia M. Correa-Torres – Associate Professor (University of Northern Colorado, USA)
- **Zika virus: a new challenge for social inclusion**
Presenter: Shirley Rodrigues Maia; Co-presenter: Vula Maria Ikonomidis (Grupo Brasil and Ahimsa Brazil)
- **The Simulator. A model or method for communication**
Presenters: Anne Nina Buss and Frank Hedegård; Co-presenter: Ann Christin Hed Pedersen (Blindecenter Bredgaard, Denmark)
- **Three Countries Connect**
Presenter: Tracey Veldhuis (DeafBlind Ontario Services, Canada); Co-presenters: Melaine Gauthier (Canada), Michael Karlsson (Sweden) & Mireya Cisne Francis Gutierrez (Nicaragua)



Poster session

DAY 2 PLENARIES

September 06, 2017: TOUCH

The morning of **Day two** of the conference featured a keynote from cognitive neuroscientist Dr. Alberto Gallace, (University of MilanaBicocca and Milan Centre for Neuroscience)¹⁰ titled “Touch and the body: tactile awareness and the science of interpersonal touch”.

A few highlights from Dr. Gallace’s keynote:

- The number of scientific studies on touch are few compared to other sensory modalities; where touch is studied it was mainly in relationship to visual impairment. This meant many questions are unanswered related to the cognitive, emotional and sensorial aspects of touch.
- The importance of touch is hugely under evaluated, despite every human activity being affected by touch, including eating, walking and human bonding.
- Touch is a ‘contact sense’ vs. vision and audition being ‘distance senses’.
- Many everyday activities that we perform are based on the processing of tactile sensations that are often carried on ‘implicitly’ in our neural system.
- Touch is a complex activity that involves aspects of perception, spatial processing, emotions as well as associated with the release of certain hormones.
- Tactile contact is extremely important for our social interactions, from a friendly handshake to romantic and sexual relationships.

Conclusions: The sense of touch is extremely relevant for our survival; it is strictly linked

to our sense of self and to our emotional wellbeing. Neural models of touch are beginning to be developed but more research is needed, particularly in the context of emotions.

Dr. Gallace’s presentation was followed by an overview from Dr. Jude Nicholas (Norway) and a rebuttal from Linda Erickson, a person with deafblindness from Sweden.

Dr. Nicholas:

Alberto Gallace’s research has put a scientific light on touch, a relatively underinvestigated sensory modality; one that has been unappreciated and undervalued. Dr. Gallace has highlighted that touch makes our world real. He illustrated how our brain processes tactile information and how touch has the latent power to change behaviour, interpersonal relationships, cognitions, emotions and social bonds. While most individuals use touch in our daily lives, individuals with deafblindness may rely increasingly on the sense of touch to experience their world.

Dr. Gallace also suggested that neuroscientific studies have shown that the tactile modality is well able to handle social communication and indeed language. Neural imaging studies in an acquired deafblind subject show that the activated brain area from touch is similar to that of spoken language. Furthermore, an electrophysiological study had found significant changes in the tactile brain area of children with congenital deafblindness, in comparison to a control group of children without vision and hearing impairment. This study



Key note speaker Dr. Alberto Gallace

suggests at the very early stages of neural development in individuals with dual hearing and vision loss that touch assumes a very important role in communication. In other words, underlying brain mechanisms connected with these senses can be modified through an increased experience with the tactile medium.

The sense of touch is very crucial for all people with deafblindness. It is significantly involved with sharing feelings with others, when engaging in social interactions as well as enhancing the meaning of the words in nonverbal communications. So, what does living with touch really mean for an individual with deafblindness? Linda Erickson will try to answer this question.

¹⁰ <https://neuromi.it>

Linda Erickson

Linda reflected on what she was receiving from touch at this moment, like sitting on a chair, touching her feet on the floor, touching something with her hand; feeling that the air was warm. She suggested that most people are not readily aware of touch. "When I am out for a walk, I feel the road, the sun or the rain", she said. For Linda there is the social aspect of touch, through a handshake, a hug, the sensation that someone is guiding me. Touch provides her a sense of emotion, sometimes positive sometime negative. Linda suggested that we all need to be more aware of touch in social settings, considering how it is given and how it might be perceived.

The afternoon panel session consisted of three presentations focussing on Touch from the perspective of individuals with acquired and congenital deafblindness.

- **Grzegorz, Kozlowski** from Poland spoke about his use of his sense of touch from several personal perspectives – education, family life, communication support, recreation and emotional and spiritual experiences.
- **Grete A Steigen**, spoke about her life and experiences as mother of Tormods, a 31 year old man diagnosed with CHARGE Syndrome. Grete is also President of the Norwegian Parents Association. Grete's presentation also featured Kari Schjoll Brede, a professional who works with Tormods. Kari is herself a mother of Treena, a young adult who is deafblind. Together they presented and discussed a video that demonstrated Tormod's sense of touch.
- **Karine Vassbotn** from Norway spoke about how the sense of touch plays a vital role in her every day life with deafblindness, resulting from Marshall Syndrome¹¹. Karina spoke about her years of reliance on her horse Jasper until his passing. Jasper was deeply important in her life for 13 years and provided her the opportunities to be active, receive positive movement experiences, build a stronger body and mind. Importantly, Jasper gave Karina an awareness of the sense of touch and demonstrated the vital role it plays in her life.

THE WORKSHOPS



Interpreters

- **TMIC: A fine tool to create social connectedness**
Presenter: Damie van Vianen; Co-presenter: Amanda Buijs (Kentalis Rafael, The Netherlands)
- **Arousal and interaction with people with deafblindness**
Presenter: Henrik Okbøl, Geelsgårdskolen; Co-presenters: Tina Bendixen, Lone Rømer, & Tanja Møller Christiansen (Denmark)
- **Tactile sign language in communication with people with Congenital deafblindness**
Presenter: Bettina Kastrup Pedersen (Centre for Deafblindness and Hearing Loss, Denmark)
- **Conducting psychotherapy with individuals who have acquired deafblindness**
Presenter: Maj Volden (The Norwegian National Unit for Mental Health and Deafness, OUS-HF, Norway)
- **The formation of the communicative partner image for the deafblind students**
Presenter: Svetlana Zarechnova (Children's House for Deafblind, Russia)
- **Positive Touch Access: Invitation to Touch Leads to Self-Actualization**
Presenter: Susanne Morrow (New York Deaf-Blind Collaborative, USA)
- **'Life in resonance', a personal exploration of communication through touch as a deafblind shiatsu therapist**
Presenter: Femke Krijger (Own practice of shiatsu/Tao yoga therapy 'levensvonk', The Netherlands)
- **Narrativity and embodiment**
Presenter: Myrra Smith; Co-presenter: Dorte Lindberg (Centre for Deafblindness and Hearing Loss (CDH), Denmark)

¹¹ <https://rarediseases.org/rare-diseases/marshall-syndrome>

DAY 3 PLENARIES

September 07, 2017: Closeness

- **Adventurous learning and declarative communication in a tactile multipartner way**
Presenter: Amanda Buijs; Co-presenter: Lieke van Buuren (Royal Dutch Kentalis, Rafaël school, The Netherlands)
- **Teaching Orientation and Mobility Skills to people with deafblindness who use tactile sign language**
Presenter: Meredith Prain; Co-presenter: Bronwen Scott (Senses Australia, Australia)
- **The art of sight**
Presenter: Sylvia van Doorn; Co-presenters: Ans van Gulick, Annet Eikelboom and NN (Royal Dutch Kentalis, Unit Deafblindness, The Netherlands)
- **Deafblindness, Self-Stimulation, and Availability for Learning**
Presenter: David Brown (Self-employed, USA)
- **The support needs of family members of persons with Usher type 2**
Presenter: Ilse van Zadelhoff, Co-presenter: Saskia Damen (Royal Dutch Kentalis, The Netherlands)
- **Enhancing learning for a child with deafblindness by putting on the 'cognitive glasses': Assessment of learning through working memory**
Presenter: Anne Schoone; Co-presenter: Monique Verberg (Royal Dutch Kentalis, The Netherlands)
- **Group training for communication of young adults with visual and hearing impairments**
Presenter: Alina Khokhlova (Yasenevo Center for Deafblind, Russia)

The opening plenary of Day three first featured a presentation titled: **A Story about Needs and Desires from Professor JPL Slaets, Leyden Academy on Vitality and Ageing, The Netherlands**¹².

In this presentation Dr. Slaets spoke about the difference between care orientated to needs verses care orientated to desires.

He explained the distinction between two different domains related to the quality of care. The first domain is traditional medical care which is focused on treating illnesses, impairments and disabilities. The second domain which is little discussed has much to do with 'what matters to the individual' in the sense of positive well-being, which is not about needs in the medical sense but about wishes or desires.

Professor Slaets believed that the most important source of wellbeing for individuals, either from a personal or a medical perspective, is developing personal closeness relationships with individuals. And a special form of closeness is **touch**, one of the most important expressions of closeness.

From either a patient-physician perspective or a private relationship, being touched emotionally and physically relate to the primacy of touch in human life, a fundamental of all human desires. People – patients want to be touched; at the same time people want and need empathy in care. As physicians, sensitivity and critical responsiveness need to be our guides when we are reflecting on complex and conflicting values during our work.

Picking up on some themes from Professor Joris Slaets keynote, the plenary continued with two speakers, first well-known professional in the deafblindness field from the UK, Liz Duncan, and Sanja Tarczay, President of the Croatian Deafblind Association and President of EDBU.

Liz Duncan:

Liz illustrated Professor Slaets theme of closeness through discussing her work with three adult individuals with deafblindness in the UK: an elderly lady one with Type 2 Usher Syndrome living in an adult care home, an elderly lady with acquired visual and hearing impairment, and a teen young man with congenital deafblindness.

For the first individual, being isolated meant her emotional needs weren't been supported despite her physical needs been satisfied She was missing her connections and her sense of closeness and touch

For the young man with congenital deafblindness, the concept of closeness was difficult for him to understand. It was difficult for him to separate being emotionally close from being physically close.

For the elderly lady with acquired deafblindness living in the residential home and feeling isolated without friends or family around her anymore, her understanding of closeness was all about emotion. But her attitude of not wanting to be there, made it difficult for staff to provide the closeness she desired, while they otherwise provided her the proper care. As Professor Slaets suggested,

¹² www.leydenacademy.nl/home-en

satisfying this person's physical needs didn't take into account the desires and the human wish that we all have: to share a relationship with another human being.

Sanja Tarczay:

Sanja presented her personal story connected to closeness and touch. She was born as a deaf person in a family of people with deafness. According to Sanja, this first example of a personal sense of closeness, belonging to the same linguistic group, continues to provide her strength today.

She described how her happily connected world vanished during her teenage years when her sight deteriorated, causing a loss of

personal connections which lead to her feeling of isolation. Seeing a doctor who provided her support; essentially treated her soul!

Following, she had the opportunity to travel to Sweden for educational purposes. While there she was diagnosed with visual impairment. Her diagnosis as being deafblind actually put her on a new study track, which led her to create new connections and realizing new opportunities. Sweden was important to her not only for her friendships but for her acceptance of deafblindness, which gave her the encouragement to return to Croatia.

Back in Croatia she learned there was little awareness of

deafblindness and people with this disability had no legal rights. She became politically active, forming an association for deafblind people called TOUCH. This allowed her to establish closeness and connections. She admitted her path was not easy as not everyone was supportive of her cause for people with deafblindness to be accepted equally in society.

Her advice to people with deafblindness is that they need to be independent. At the same time, the key to achieving our independence as people with deafblindness and feel the closeness to the world and people around us is to have the support of qualified interpreters.

THE WORKSHOPS



Workshop featuring Vanessa Vljakovic

Communicative engagement in multiparty conversations with persons with CDB

Presenter: M. Worm (Bartiméus, The Netherlands)

- **Teaching concepts to Children using the BEST Elements of Dance**

Presenter: Kristen Paul;
Co-presenters: Brooke Barnhill, Catherine Nelson & Pamela Geber Handman (University of Utah, USA)

- **Research programme Communication and Deafblindness: Overview and new research**

Presenter: Marleen Janssen,
Co-presenter: Saskia Damen (University of Groningen, The Netherlands)

- **From thoughts to language to reality – getting closer to social connectivity**

Presenters: Sabine Brink & Ole Wøssner; Co-presenters: Tanja Nyons & Litte Frehr (CFD – Døvblindehuset, Denmark)

- **From Sensory to Symbolic**

Presenter: Basem AbdelGhaffar (University of Sharjah, United Arab Emirates)

- **Sailing Sense – Sailing for people with deafblindness and multi-sensory impairment**

Presenter: Miguel Olio (Sailing Sense, Brazil)

- **The important role that touch has played in my life**

Presenter: Vanessa Vljakovic (University Student, Australia)

- **Affective sense of touch and movement in shaping closeness**

Presenter: Ivana Macokatic,
Co-presenter: Ana Katusic (Day-care Centre for Rehabilitation Mali dom Zagreb, Croatia)

- **What does language mean for me?**

Presenter: Annika Maria Johannessen (Statped, Norway); Co-presenter: Olaug Grude Hobberstad (Klepp kommune, Norway)



Scott Davert speaking during Day One afternoon plenary

RESEARCH SYMPOSIUM PROGRAM

- **Adult children of parents living with Usher syndrome: Experiences across the life span**
Presenter: Karen Wickham (Senses Australia, Australia)
- **Autonomy support for students with congenital and acquired deafblindness: how can it be assessed and addressed?**
Presenter: Ineke Haakma (University of Groningen, The Netherlands)
- **My isolation makes me fear that I'll forget how to communicate**
Presenter: Rikke Norup Christiansen; Co-presenters: Karin Moreau Andersen and Malene Kure Strandkvist (CFD Rådgivning, Denmark)
- **Come to shared knowledge in 1 day!**
Presenter: Sonja van de Molengraft;
Co-presenter: Guillaume Ferron Séverine Clément (CRESAM, France)
- **Trapped in Deafblindness – The Story of A Man with Acquired Deafblindness** Presenter: Anette Kjær; Co-presenter: Jette Mistegård Jørgensen (CFD Councelling, Denmark)
- **Health and people with Usher syndrome, need for biopsychosocial approach**
Presenter: Moa Wahlqvist, (Audiological Research Centre, University Hospital of Örebro, Sweden)
- **A guide for supporting people living with deafblindness through their palliative journey**
Presenter: Lorraine Simpson (DeafBlind Ontario Services, Canada)

Other Activities scheduled for Day 3 included:

The Research Symposium; The Great Debate: How does Ethics, the Economy and Human Rights; Visit to the Centre for Deafblindness and Hearing Loss

- **The lived experience of vulnerability amongst adults ageing with deafblindness**
(Peter Simcock)
- **Problems identified by dual sensory impaired older adults**
(Lieve Roets-Merken & Maud Graff)
- **Prevalence of older adults in Sweden with combined severe vision- and hearing loss**
(Elin Lundin)
- **Working with Deafblind people to develop a good practice approach to consultation and research activities**
(Alana Roy)
- **Work, health, social trust and financial situation in persons with Usher syndrome type 1**
(Mattias Ehn)
- **Employment participation of deafblind people**
(Nadja Högnér)
- **ISTAT Research and future scenarios**
(Patrizia Ceccarani, C. Ricci & A. Solipaca)
- **See and Listen to Me**
(Ann-Britt Johansson)
- **Bringing Adults with Deafblindness from Margins to the Centre of Research**
(Atul Jaiswal via skype)
- **Intersubjective communication development between students with deafblindness and their teachers**
(Kirsten Wolthuis)
- **Close correlation between staff education, competences, transfer and organizational learning**
(Anne Søbye & Helle Buelund)
- **Measuring social connectedness through adapted physical activities (APA)**
(Marijke Bolwerk, Lotte van de Ween, Mads Kopperholdt & Anders Rundh)
- **Communicative Forms & Functions Used by Individuals with CHARGE Syndrome**
(Susan M. Bashinski)
- **Evaluation of symbolization' level in children with visual and hearing impairments**
(Alina Khokhlova)
- **Evidenced-based practices in communication, literacy, and social-emotional development**
(Susan M. Bruce)
- **Connectedness by ongoing focus on the bodily-tactile modality** (Joanna Wisniewska)
- **Overview of videofeedback interventions aimed at enhancing social interactions**
(Saskia Damen & Meredith Prain)

ETHICS, ECONOMY AND HUMAN RIGHTS – THE GREAT DEBATE

How do ethics and economy merge?

A political perspective of a stronger teamwork between human rights and economy

The objective of this event was to bring politicians from different levels, board members, headmasters, CEO's and members of organizations together to talk about how ethics and economy merge.

The debate featured:

- **On Ethics:** Britta Kusk Nørgaard, Assistant Professor in the field of social education, University College Nordjylland¹³;
- **On Human rights:** Richard Hawkes, CEO, British Asian Trust, one of Prince Charles's charities that works across South Asia supporting people out of poverty

- **On the Economy:** Knud Aarup, the chairman of the Board of the Danish Social Welfare Society¹⁴ and chairman of the Board of the Red Cross Branch in Aarhus, Denmark.

The moderator for the events was Jonas Bergströ, Manager of the Disability Unit at the Nordic Welfare Centre



Volunteers

DAY 4 PLENARY

September 08, 2017: Future of the Deafblind Field

From the Perspective of DbI: Frank Kat, DbI Vice President

DbI is an international organisation focused on the needs of individuals who are deafblind, including a focus on families and the professionals who provide services.

To predict DbI's future, Frank suggested that we need first to understand where we came from to appreciate where we are today.

DbI's roots go back to the late 1950's and 1960's when international contact (by traditional mail) was among educators in Europe and North America. Following this period was the spirit of advocacy dominating the late 1960's and 1970's, with the emerging movements for

rights and equal opportunities for people with disabilities.

Skipping back to 1962, the first gathering of this new group occurred in the UK with a conference called 'Teaching Deafblind Children'. Attended by forty-one professionals working then in the field. Many conferences followed primarily in European countries.

By the late 1960s rapid changes were happening in the field. Deafblind education continued to be important, but service delivery for all people with deafblindness took on increased importance. Parents were demanding more influence and happily, more programmes were developing worldwide.

Originally called IAEDB (International Association of

Educators of the Deafblind), Deafblind International officially became a worldwide organisation in 1999 at an international conference in Lisbon Portugal.

Skipping ahead to 2012–2017, the focus on human rights in the field has evolved from a medical model to one with a social perspective, with inclusion being the focus. A 1984 report from UNESCO adopted the 'Salamanca Statement' which called on the international community to endorse the approach that for the education of disabled children, that inclusion should be the norm.

In the present day, DbI networks reflect the main issues in the deafblindness field. While we continue to have the long standing networks (Acquired Deafblindness

¹³ <https://www.ucn.dk/english/home>

¹⁴ denmark.dk/en/society/welfare

and Communications), we have established such newer networks as: Network of the Americas, Usher Syndrome, CHARGE, Youth and Outdoor Networks, all of which function as the backbone of Deafblind International.

DbI is a healthy organisation today, but it can only prosper through participation of its members, which is currently around 200 members. Our strategic planning has changed **from** using statements like ‘enhancing organisational capacity, encouraging improvements in practice and creating new knowledge’ to focussing on ‘diversity, sharing knowledge, supporting networks, strengthening connections and partnerships’. We do this by investing in technology and

social media to allow us to connect more.

So, what will our future be like? One thing that should not be different from before will be our continued focus on supplying information through conferences, our website, our magazine DbI Review and social media. A significant part of our future will be our increased use of technology and expanding our organizational partnerships. Currently we partner with International Council for the Education for the Visually Impaired (ICEVI)¹⁵ and World Federation of the Deafblind (WFDB)¹⁶, but we need to expand our partnerships to include other disability

groups and organizations, the medical field and the UN. More research should also become a priority. However, our focus will always be about improving the daily lives and legal rights of individuals with disabilities.

So simply stated, DbI will grow as a network organisation; becoming more diverse and extending its partnerships. Through more memberships we will become a more global network for professionals, researchers, families and most of all as a partner for persons with deafblindness. DbI will continue to organise and support conferences because that is where we meet, exchange ideas, share stories and have fun. DbI will be able to do that with help from everyone in the field. Will you join us in the future?

**From a Family Perspective:
Stephen Wiik**

Stefan Wiik from Sweden, introduced himself as a parent of Martin (a 24 year old multi-disabled man, born premature, with severe cerebral palsy and congenital deafblindness) and a long-time member of the parent’s section of the Swedish Association for the Deafblind.

In preparation for his talk about the future from a parent’s point of view, Stephen developed an online survey with other parents to learn the needs for their children’s future. Not too surprisingly the issues reported were: school development; personal assistance for the children in school or at home; health care; communication; improved opportunities during leisure time; accommodation opportunities outside the family home; working life opportunities in adulthood,

etc. While parents seemed generally quite satisfied with their child’s level of communication skills and health care; their concerns were largely about adult services. These same issues concern parents all over Europe.

How do we get the authorities to understand the needs of disabled persons, recognizing that agencies are facing reductions in funding? As parents, we are not strong enough on our own and need assistance to develop long term adult support.

Coupled with that are increased family stresses with our children

transitioning into adulthood, with the never-ending requirement for contacting various health specialists, social services staff, politicians, etc. Many parents just don’t know where to turn!

Parents largely are seeking alternative living arrangements for their adult children, so they can live as much of an independent life as they can. Availability of these options are limited. Holistic thinking at all levels, with individualized services based on individual needs should be our goal, according to Stephen.

“Holistic thinking at all levels, with individualized services based on individual needs should be our goal, according to Stephen.”

¹⁵ www.icevi.org

¹⁶ www.wfdb.eu

From the Perspective of Deafblind Persons: Sanja Tarczay, President Croatian Association

According to Sanja, all deafblind people with acquired deafblindness need to take the lead role and take the decision making into their own hands through their own organisations. As Helen Keller said, there's not many things we can do alone but together we can do so much.

Having said that, Sanja provided a bit of background history about why deafblind people were slower than other disability groups to organize. The World Federation of the Deaf¹⁷ was established in 1951 and it was 50 years later before the World Federation of the Deafblind was created in New Zealand in 2001.

Why this delay? Many countries did not recognize deafblindness; for some the terminology was confusing. Many deafblind people were/are trapped in their deafblindness; not accepting their condition and/or struggling to adjust to their reality. Many feel too tired which leaves them little space and time for other activities. On top of that, suitable professional services (ie interpreters) are in short supply, or of poor quality or non-existing. This all affects the possibility for deafblind people to be visible.

Sanja reiterated the motto: nothing about us without us. We want and need to be more inclusive, and one way for this is to have our own dedicated organizations. They exist in many countries but not all.

Sanja spoke about the European Deafblind Union (EDbU)¹⁸ which began in Finland in 2003, when deafblind persons primarily from



Frank, Stephen, and Sanja

the Scandinavian countries were brought together for a meeting. Its first President was Owe Bejsnap, a deafblind person from Denmark. EDbU is the voice of deafblind people in Europe who are struggling every day to achieve equality and the rights of persons with deafblindness in Europe.

Today, EDbU has 19 members from Hungary, Bulgaria, Sweden, Spain, many with Usher Syndrome and other syndromes. Members use various means of communication to share knowledge and experiences. More members are welcome.

The organization is active in a number of areas, including: empowering deafblind people to take decision making into their own hands; exchanging knowledge to organise conferences and seminars to help deafblind individuals in their own countries; political lobbying and campaigning; establishing more local collaboration and partnerships. A recent partnership was established with the European Union of the Deaf¹⁹.

EDbU has also established a connection with EDbN²⁰, a Network of DbI that focusses on individuals with congenital deafblindness. EDbU believed that working together with this group would make a difference in influencing decision makers.

Recently, EDbU attended the European Parliament, raising awareness of deafblindness and establishing great contacts which should help the organization to become better recognised in the future. To foster this awareness, EDbU has moved its centre of operation to Brussels to be better connected to fight for deafblind persons rights.

Another exciting venture for EDbU was establishing an EDbU woman's group. Sanja suggested that women will play a big role in the future of the organization.

In closing, Sanja called for a united movement to travel to Spain in 2018 to participate in the WFDB meeting.

¹⁷ <https://wfdeaf.org>

¹⁸ www.edbu.eu

¹⁹ www.eud.eu

²⁰ edbn.org

FINAL KEYNOTE PRESENTATION

‘Understanding Søren Kierkegaard’

Joakhim Garff, Kierkegaard Scholar at the Søren Kierkegaard Research Center, University of Copenhagen²¹

Joakhim Garff, a Kierkegaard scholar, presented a spirited review of Kierkegaard’s life and philosophies. His presentation was based upon his biography of Kierkegaard, titled: *Søren Kierkegaard: A Biography*²².

Søren Aabye Kierkegaard was a Danish philosopher, theologian, poet, social critic and religious author who is widely considered to be the first existentialist philosopher. He wrote critical texts on organized religion, Christendom, morality, ethics, psychology, and the philosophy of religion (Wikipedia).

THE CLOSING SESSION

Closing Remarks by Jude Nicholas, Chair Scientific Committee

Jude, on behalf of the Scientific Committee, expressed gratitude to all those who made this event a success, including the over 500 participants coming from 30 countries. So many people have contributed in so many ways to turn this event into a smoothly run conference with many interesting workshops, networks, poster presentations, exhibitors within a very good atmosphere for discussions and networking. Jude also expressed gratitude to the volunteers for their overall support and help during the conference.

Many of you have said to me that this was a great conference. Thank you for being so, positive. Thank you all for the excellent contributions and I wish you all a safe journey home.

“Many of you have said to me that this was a great conference.”

Closing Remarks from Gill Morbey, President DbI

Gill first thanked the communicators and interpreters who have done a stunning job working through the many technical presentations, including Elaine for her closed-captioning work which she had done throughout the entire conference totally on her own!

Since the main sensory modality for the majority of us is still vision and hearing, it is difficult for us to comprehend how significant the sense of touch is. Perhaps that is one of the reasons that we sighted and hearing people actually miss so much.

Gill further related to a few presentations and key words expressed during the conference including touch, closeness, connections, transfer of modalities, identity, bringing together congenital and acquired deafblind individuals, labelling, rights etc

Gill reminded the audience that one of DbI’s priorities is diversity. This is not about being politically correct; it is because if DbI does not diversify we will miss the richness from other countries that colleagues and friends bring.

She finished a story that was mentioned at the beginning of this conference when Richard Hawkes was talking about a young woman that he knew living in a remote



Communication

village in India. She is grown up now, in her early 30s. Because she's disabled, she received extra points for her village. As a result, she was able to electrify the village and she received the first toilet in her village. This lady now runs a local snack shop and her elderly father (who once laboured in the fields) has been able to give up his labouring work in the fields to keep her accounts. How great is that! Everyone has a value!

Gill mentioned that despite being 40 years in this field, she always learns something at conferences

and "I've learned so much at this one, which reminds me why we do this work. The contributions have all been brilliant, including the stories that individuals were so brave to share. So on behalf of DbI, a deep thanks to everyone involved."

Gill went on to say that: "It is a tradition to announce where the next conference is going to be. When Lars Sobye opened the conference, he pointed out that this event is much larger than a usual European Conference; he is correct in that it is in fact an international event. So DbI is changing its

process for conferences a bit. Our next DbI conference of course will be the World Conference planned for Australia in 2019. We still intend to have regional conferences; but we will have more of them...not just in Europe. So instead of the next regional conference being somewhere in Europe in 2021, we're going to have the next regional conference in Africa! We don't have the details about when or where in Africa, but I can assure you that we'll be announcing more details in the coming months. Thank you very much."

Presentation of Life Time Achievement Awards by Bernadette Kappen, Vice President DbI

Bernadette said: that each time we come together in one of these large gatherings, DbI is so happy to be able to honour people who have contributed so much in their careers to people that are deafblind. Today is no

exception. We ask each time when we have these events for people to be nominated for these awards. There will be an event in 2018 for the Conference of Americas, and once again in 2019 for the world conference. So, please think about this; we all know people in our lives who have contributed so much to people that are deafblind."

The first presentation of the life time achievement award

was to Dorte Schultz Nielsen from Denmark. Lars Sobje accepted the award on her behalf. The second presentation of the award was to Evabritt Andreassen from Norway.

The award includes a Crystal tower with a globe at the top, and the DbI logo that says Deafblind International Lifetime Achievement Award.

Closing Remarks from Lars Sobje, Chair Local Planning Committee

In his closing remarks, Lars first thanked DbI for trusting the Danish organization to organize this successful conference. He expressed thanks to the Scientific Committee for producing such an excellent programme with so many qualified lecturers, workshops and poster sessions. He also thanked the local organization committee, the many volunteers, the technical people and the incredible interpreters that put all the initial planning together to make this conference such a great success. Finally, Lars expressed his thanks and great pleasure to host so many people coming to Aalborg.



Conference Centre

Article assembled by the editor from transcripts supplied by the conference committee.

A new DbI Network was formed in Aalborg

Mads Kopperholdt and Anders M. Rundh

During the DbI European Conference in Aalborg 2017, a new Network within DbI was founded.



Mads Kopperholdt and Anders M. Rundh

The idea of the network came from a European COMENIUS-project¹ between the Center for Deafblindness and Hearing Loss (CDH)² (Denmark) Kentalis³ (The Netherlands) and Åsbackaskolen⁴ (Sweden). Through this project we learned the benefits of participating internationally with respect to working with Adapted Physical Activity (APA) both in school settings and in leisure activities.

The new network, to be called Adapted Physical Activity (APA), will be all about international sharing of information and taking part in discussions about theory and practice.

What is APA?

Adapted Physical Activity (APA) has been recognized as being an important part of the pedagogical approach of the Physical Education Program of schools in many parts of Europe. APA is recognized as a key practical approach to encourage people with a functional disability to participate in sport or movement activities together with other people. This approach utilizes methods which make sporting activities accessible to everybody through focusing on possibilities rather than limitations. The methods of APA are directed towards the interests and competencies of the individuals at a given time. The

activities are adapted by changing and adjusting the rules, environment, equipment and teaching style to give the individual the best possible conditions for participating. While joy and desire to participate are the driving forces in all activities, an APA approach can also be used to achieve other benefits such as health and confidence without losing the joy and desire to participate.

For several years we have been teaching an APA class at CDH, experiencing some great results with the students, not only physiologically but with improved communication and social interaction among students. Our focus is that students do all their activities together as a pair or together with a group rather than 1 on 1 with a professional. As a result, we have observed that the level of student's motor skills and social skills has increased not just in the APA class but during their schooling and leisure time as well.

Acquired Deafblindness Network

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¹ https://en.wikipedia.org/wiki/Comenius_programme

² The Centre for Deafblindness and Hearing Loss (www.dbc.rn.dk) is a small corporate member of DbI.

³ Kentalis (www.kentalis.nl) is a large corporate member of DbI.

⁴ Åsbackaskolen is a special education school operating under the authority of the Special Educational School Authority in Sweden (www.spsm.se)

Aims of an APA Network

To participate through an international internet based forum to:

- Exchange knowledge of APA (Adapted Physical Activity)
- Post the latest ideas, news, practical exercises, theory and scientific research.
- Participate in conferences and exhibitions.
- Meet every other year, to present and discuss the new theories and best practices.
- Our plan for the first face to face meeting is suggested to be at the 17th Deafblind International World Conference in Australia in 2019.

How to become a member of APA Network?

To become a new member of the Network, individuals should send a 'letter of introduction' to either of the co-chairs, after which they will be added to the 'Deafblindness & APA' Facebook group. Individual letters of introduction will be posted so everybody will see who is joining the group.



Network group in Aalborg

Current Network Makeup

Mads Kopperholdt – Co-Chair, (mads.kopperholdt@rn.dk)
Anders M. Rundh – Co-Chair, (anmaru@rn.dk)
Miguel Martin Olio – Vice Chair, (miguelmartinolio@gmail.com)
Marijke Bolwerk – (m.bolwerk@kentalis.nl)
Lauren Lieberman – (lieberman@brockport.edu)
Simon Allison (simon.allison@sense.org.uk)

We hope you can join us!

CHARGE Network

Gail Deuce

The CHARGE pre-conference, held on 4th September 2017, was attended by approximately 70 people.

For more information about the pre-conference, contact Gail Deuce at gaildeuceconsultancy@gmail.com

The programme was varied with speakers from across the world sharing their experiences and knowledge of working with individuals with CHARGE. The day included the following presentations:

- David Brown (USA): Posture and Movement
- Sharon Grassick (Australia): What is Fun Chi? (This included a practical session much enjoyed by all)
- Marga Leefkens (Netherlands): The role of vision and touch in joint attention (Marga was unfortunately unable to attend in person due to personal circumstances, but it was great that she was willing to provide a video recording of her presentation and joined us for part of the day via Skype – the joy of modern technology!)
- Gail Deuce (UK): Making friends – Supporting the development of friendships in school
- Susan Bruce (USA): Socialisation dyads of older and younger students
- Lynn Skei, Annette Simonsen Sølgaard & Jette Nørregaard (Norway): Self-identity of young adults
- Susan Bashinski (USA): Beginning of a lifeline

At the end of the day David Brown explained he had set up the DbI CHARGE network group in the hope that people would join together to share their knowledge and experiences of working to support individuals with CHARGE. It was great to see the growth of this group and the networking that occurred during the day.

A big thank you to all the speakers whose presentations were all well-received and to Inge Mogensen from Denmark, who worked hard behind the scenes dealing with all the practical issues and ensuring everyone was fed!

CHARGE Syndrome: Supporting the Development of Peer Interactions in School¹

Gail Deuce

Part of being human involves forming relationships with others that support our social connectedness. Any child or young person who is deafblind is likely to be at greater risk of social isolation, and this is apparent in many individuals with CHARGE who ‘struggle to behave in a manner that promotes social relationships’ (Hartshorne & Hartshorne, 2011, p.205).

CHARGE syndrome is a complex condition with a wide range of anomalies that have the potential to impact upon social and emotional development, including establishing meaningful peer relationships. This might include their sensory impairments, poor communication skills, self-regulation issues including difficulty recognising their own emotional state and empathising with others, executive function difficulties (e.g. initiating social interactions, difficulty shifting their attention).

The child or young person’s environment may also be a contributory factor, such as the knowledge and skill of adults to facilitate peer interactions in the school environment, and whether the child with CHARGE has access to an appropriate peer group.

It is important therefore, that those working to support learners with CHARGE in the educational setting, seek to address this issue and rise to the challenge of identifying and implementing strategies to supporting the development of social relationships in school.

What research tells us

Research undertaken by Deuce (2015) found that teachers reported the pupil with CHARGE in their class was considered to have developed meaningful relationships with a number of adults (on average 5.73 relationships) in the educational setting. In contrast, teachers perceived the same group of learners to have established fewer relationships with their peers (an average of 1.73), but with half of the cohort perceived as having established no meaningful peer relationships at all.

This corresponds with earlier research undertaken by Hartshorne and Cypher (2004), where a primary concern expressed by parents related to their child’s difficulty in establishing same-age relationships. Work by Souriau et al (2005), found individuals with CHARGE showed a preference for adult

rather than peer relationships and for relationships to be conducted on a one to one basis. They also reported that those individuals studied with CHARGE had difficulty with social exchanges, turn-taking and the understanding of social rules.

What strategies might help in the school setting

Teachers working with learners with CHARGE will frequently express the view that these individuals are often very social aware but, at the same time, often socially inept – they are interested in the activities of their peers and want to form relationships, but find it difficult to do so. This highlights the need to focus on how the development of meaningful peer relationships might be supported.



Peer interaction on a trampoline

¹ The paper was presented at the CHARGE Pre-Conference in Aalborg, Denmark, September 04, 2017

Understanding of their own emotions and regulating their emotional state

At the DbI CHARGE pre-conference in Aalborg, 2017, David Brown explained that many individuals with CHARGE struggle to remain 'in touch' with their physical bodies. Given this, we should perhaps not be surprised if these individuals are also found to experience difficulty connecting with their own emotional state (Deuce, 2017).

- In response to this, a structured emotional literacy programme is likely to be needed that can support the child or young person to develop an understanding of their own emotions and those of others, and to regulate their own emotional state (see Kennert et al, 2015)

Social skills

It is important to ensure the learner with CHARGE knows how to behave appropriately in social situations and learns the necessary social skills to enable them to actively participate in activities alongside their peers.

- Small group activities, supporting the learner with CHARGE to learn how to participate appropriately in a small group
- Learning how to respond to requests, questions or instructions from the class teacher
- Understanding the rules of the classroom, including tidying their work, lining up, sitting still on the carpet with the rest of the class
- Create a social skills group where the focus is

on learning to initiate and sustain social interaction sequences, the development of turn-taking skills, and so forth

- Make use of role play and social stories to practice social situations and consider different ways of responding within these situations. It can be helpful to use puppets/figures to re-enact a situation that has arisen; this provides a concrete support that is known to be important for learners with CHARGE (Deuce, 2015), and also provides a degree of separation from the child and the social situation that s/he may have found quite difficult

Linking up with peers

- Ensure access to a peer group with appropriate communication skills; for example, if the learner with CHARGE is a sign language user, they will need access to peers who are also able to communicate using sign language
- Promote connections and common interests
- Establish a 'buddy' systems, pairing up pupils strategically (for example, where there is a common interest)
- Foster peer support (e.g. using a 'Circle of Friends')

Shared experiences

- Use sharing activities, such as carrying a box together, sharing teaching resources
- Use play to facilitate social and emotional awareness
- Schedule small group work into the timetable with a consistent group of peers

- Provide sharing activities that all can equally participate in and enjoy

Break-time

Break-time can be one of the most difficult parts of the school day for the learner with CHARGE, possibly due in part to the lack of structure, less adult involvement, and lack of predictability. In response, it can be helpful to:

- Ensure there is an adult to model and facilitate interactions between the learner and his/her peers
- Set up structured play activities that might include providing some play equipment to focus on, and use of games with simple rules (e.g. hide and seek), making sure the learner with CHARGE knows the rules of the game
- Provide a smaller, quieter space for a small group of peers to play together
- Provide a safe space for individual or group conversations (e.g. providing the space and facilities to make a cup of tea and share it with friends)

Classroom culture

- In the classroom the teacher should show their approval of the work and behaviour of the learner with CHARGE, and that they enjoy being around the child, which can increase the social standing of the child in the class
- Establish a classroom culture that allows for differences and celebrates what makes each child unique
- Accentuate the positives, and developing a reward

system for helpfulness, consideration to others, etc.

- Give the child with CHARGE responsibilities (such as giving out books, cleaning the board) that will again help raise their profile and standing within the class

Learners with CHARGE at an early developmental level

Where a teacher is working with a learner with CHARGE who is at an earlier developmental level, and perhaps has more complex needs, it can be more difficult to support positive peer interactions. Two tools that might be helpful are:

- The Engagement Profile and Scale (EPS) (Carpenter et al., 2015). This tool encompasses seven different indicators of engagement (awareness, curiosity, investigation, discovery, anticipation, persistence and initiation) and supports adults to identify those activities when the individual is most constructively engaged in activities
- The Leuven Scales for Well-Being and Involvement (Laevers and Heylen, 2003) These two scales can be used to support observations to identify activities that are most motivating and of interest to the child with CHARGE

The information obtained from both tools can then be matched to other children with similar preferences for identifying activities likely to encourage parallel play and peer interaction. For example, using this approach it was noted in one particular child

with CHARGE who was most alert, engaged and showing enjoyment when using a resonance board. Another child was identified who also enjoyed the resonance board and the two children were then placed together on the board. This resulted in the two children becoming aware of each other, and an early connection being made between them.



For more information, contact Gail Deuce at: gaildeuceconsultancy@gmail.com

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Outdoor Network

Joe Gibson reports:

This has been a very busy and productive period for the Outdoor Network. The network was very well represented at the recent DbI conference in Aalborg with many members presenting posters, workshops and some even presenting from the plenary stage. The importance of outdoor and physical activities now seems to be acknowledged and recognized in many different countries. During the network session at the conference, we heard about projects from The Netherlands, The United States and Australia. While at the conference there was also the opportunity for delegates to try some adapted cycles and have a sailing experience offered by Sailing Sense from Brazil.

Shortly after the DbI conference the annual outdoor week was also held in Slettestrand, a small village north of Aalborg in Denmark. Participants from Denmark, Norway, England, Scotland and The Netherlands met and took part in a wide range of exciting outdoor activities including fishing, carriage riding and making food from what was found in the forest. As well as participating in the activities, people were able to meet and spend time with new and old friends. Next year the DbI outdoor week will be held in Sømådal, Norway. More information will be posted on the Network mailing list and on the Facebook page nearer the time.



New members continue to join the Outdoor Network mailing list and Facebook group. There are now 132 people on the mailing list from 23 different countries and as well there are 155 people on the Facebook group. You can find the Facebook page by searching for Outdoor Network, Deafblind International, or if you would like to join the mailing list you can send a message to Joe Gibson at deafblindoutdoors@gmail.com

Check out DbI Outdoor Network on you tube: <https://www.youtube.com/watch?v=lJKa>



Forest walking



Cooking

Research Network

Walter Wittich reports:

As the DbI Research Network moves into its third year of existence, we continue to grow and expand. As of September 2017, we now have 111 members on our e-mail contact list.

Saskia Damen and Flemming Ask Larsen, continue to maintain the Deafblind International Research Network Facebook group (<https://www.facebook.com/groups/158743377516989/>), currently at 176 members and growing. Come look us up and join in the conversation! Christine Lehane continues to maintain of our Deafblind International Research Network LinkedIn group ([www/linkedin.com/groups/8339092/](http://www.linkedin.com/groups/8339092/)), currently with 45 members and 15 different conversation streams.

The Action Research Working Group, led by Susan Bruce, continues to promote collaborative opportunities, and you can learn more about her efforts on our Research Network web page. Additional initiatives are always welcome, so please get in touch

with any of the members of the DbI Research Network, in case you have an idea you would like to share.

At the recent 9th European Deafblindness conference in Aalborg, Denmark, Saskia Damen and Flemming Ask Larsen hosted the Research Network session (with me attending via Skype). The session was well attended, and the participants discussed and contributed to the development of a priority list of activities that they would like to see the Research Network focus on. This list included the following items:

- Develop guidelines on how to include persons with deafblindness in research
- Provide information on how to conduct research with deafblind individuals
- Establish a participatory action research work group
- Foster research projects that are developed in collaboration with all stakeholders
- Make past research materials from DB conferences available on-line



- Inform us about methodological issues unique to deafblindness
- Investigate possibilities for data sharing
- Facilitate research across languages and cultures

The members of the research network will now take a closer look at these priorities. If you have any ideas for us, or other requests for research-specific information, we look forward to hearing from you, and please feel free to check out the networking opportunities on our web page (<http://research.deafblindinternational.com>) and contact us with your interests and thoughts.

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

Deafblind International Youth Network in association with TANNE – Swiss Centre of Competence for the Deafblind



ACTIVITY 2018 June 17th 18th 19th, 2018

Based in The Beautiful City of Zurich, Switzerland

ACTIVITY CHOICES INCLUDING:

- Guided Tour of the old town
- Thermal Bath & Spa Zurich
- Lake Zurich by ship
- Cable car to Zurich's local mountain
- Visit to a Fondue restaurant (local gastronomic specialties)
- Culture to touch – touching culture: Zurich's cultural life
- Zurich's club scene
- Free youth network hoodie or t-shirt



Bookings through the youth network Coordinator simon.allison@sense.org.uk

TOTAL COST including hotel and all activities is just £300 British Sterling (per person)

Usher Network

Emma Boswell reports:

The Usher Network pre-conference was held in the beautiful city of Aalborg, in Northern Denmark, September 03 and 04, just prior to the DbI European Conference. People travelled from Brazil, Australia, Canada and all over Europe to attend this unique blend of all things-Usher, including research, personal experiences and information on wellbeing. There were speakers from a number of countries including several with Usher syndrome.

There were six people with Usher syndrome attending the network including the speaker, Gavin Dean who opened the conference with a presentation of his research. There was also a family panel which included three people with Usher and their family members involving many different communication methods in.

For delegates to access information during the pre-conference, we organised such communication supports as: a speech to text reporter, interpreters and hands-on interpreters. This was no small feat considering some people's first language was not English or British Sign Language. Without this communication support, the conference would not have been as inclusive as it was, permitting diverse points of view.

There was a real sense of togetherness during the event, and as someone with a personal experience of Usher, I am always so inspired by others who have achieved so much in their life. It was a privilege to listen to their stories / experiences which made the conference, for me, all that more special.

Our first plenary was from Gavin Dean, who has Usher Type 3, and works as a Physiotherapist. Gavin's presentation was an overview of his MA thesis titled: "The impact of Usher's on psychosocial wellbeing: A personal and research perspective." During his presentation he talked about Usher syndrome and its psychological effects in comparison to the general population. Gavin shared both professional and personal experiences which only served to make his talk richer.

This was followed by Professor Andrew Webster from Moorfields Eye Hospital¹ and Dr. Mariya Moosajee² from Great Ormand Street Hospital, who jointly talked about the latest research into a new treatment for people with Usher syndrome. We had two question and answer sessions with both specialists, which sparked some stimulating debate.

After a delicious Danish lunch, we ran a family panel session led by committee member Karen Wickham. This comprised of Gavin, his partner Steph, a mother and a

daughter with Usher type 2 from Denmark and Alison Marshall from the UK, a mother of three who has Usher type 1. This was the audience's opportunity to ask questions about the panel's experiences of having Usher syndrome and family life.

Mads Kopperholdt and Anders Martin Rundh from Denmark then explained their concept of the importance of making all exercise suitable for deafblind children during their presentation entitled "Adapted Physical Activity: from idea to reality." They then challenged the audience to test drive their very own patented light box (see pictures) and some specially adapted bikes!

The following day we had the pleasure of welcoming Alana Roy from Australia, talking about the findings from her study on "Good practice approaches for research and consultation processes for people with Usher Syndrome». We enjoyed her unique research techniques involving interpreters and people with Usher attending 'world cafe' style sessions.



¹ www.moorfields.nhs.uk

² www.gosh.nhs.uk/

Professor Lisbeth Tranebjærg from Denmark, spoke about the “Delay in diagnosing Usher syndrome and atypical familial cases” and the Usher network’s very own Bettina Kastrup-Pedersen from Denmark talked about working with children with Usher syndrome and the fascinating work they have been doing in aiming to “give skills to usher children to allow them to grow into assertive and confident adults”. The final presentation was also from a network committee member, Tatiana Bagdassaryan from Russia, who gave a touching talk about her personal experience having Usher syndrome and explained about the services available in Russia to Deafblind people.

The Usher Network pre-conference was organised by the Network members Emma Boswell (Chair, currently working at Sense UK), Karen Wickham (Senses Australia), Bettina Kastrup-Pedersen (Center for Deafblindness and Hearing Loss, Denmark), Nadja Hogner (Department for Rehabilitation/Counselling/Deafblind, Germany), Constance Watters-Miles (Research Assistant, USA) and Tatiana Bagdassaryan, (Deafblind activist, Russia). The event was hosted by Emma Boswell.

DbI Usher Network has updated information about the pre-conference and some photographs

of the whole event. There are also the speakers’ presentations and videos. Please see the link: <http://usher.deafblindinternational.org/activities.html> <<http://usher.deafblindinternational.org/activities.html>



For more information, contact Emma Boswell, Usher Network Leader at: emma.boswell@sense.org.uk

Update on Usher Syndrome Medical Research and New Treatments on the Horizon

Dr. Mariya Moosajee

**Consultant Ophthalmologist and Senior Lecturer in Genetic Eye Disease
Moorfields Eye Hospital, Great Ormond Street Hospital for Children and
UCL Institute of Ophthalmology**

It was an absolute pleasure to be able to contribute to the DbI Usher Network Pre-conference in Aalborg, Denmark in September this year. Prof. Andrew Webster and I were able to send a video message providing an update into the research underway for Usher syndrome followed by a live question and answer session. Some of the highlights from our talk involved our progress to improve genetic diagnostic rates, gather information on the natural history of Usher syndrome and potential treatments on the horizon.

In the UK, the Department of Health initiated a research project called the 100,000 Genome Project with the premise to sequence the whole genetic code (genome-consisting of 20,000 genes and 3 billion letters) of 100,000 NHS patients, half with rare disease, including Usher syndrome, and the other half with cancer. For more information please visit <https://www.genomicsengland.co.uk/the-100000-genomes-project/>. Moorfields Eye Hospital has already recruited over 2000 patients into this study and it will help

increase our diagnostic rates for those without a genetic diagnosis. Knowing your genetic diagnosis will enable individuals to enter into research studies and forthcoming clinical trials.

This brings me to research studies that are currently underway for Usher syndrome. In my laboratory at UCL Institute of Ophthalmology, my research team has been developing disease models of Usher syndrome to understand the disease mechanisms and develop new treatments for patients. One such model is taking a small piece

of skin (around the size of a lentil) from a patient, converting the skin cells into stem cells and then reprogramming them to develop into retinal cells using stem cell technology. This provides a human retinal model of Usher syndrome. I have recently been awarded the RP Fighting Blindness Innovation Award to develop a novel form of gene therapy for Usher syndrome. The most common disease-causing gene is *USH2A*, which is very large in size. Viral gene therapy can only deliver genes of a limited size (~10 times smaller than *USH2A*), hence this is not a viable option for patients with genetic mutations in this gene. Our new project is looking into using an alternative gene delivery system, which avoids the use of viruses. It takes advantage of a human DNA element called scaffold/matrix attachment regions (*S/MAR*), which help our DNA fold correctly. These *S/MAR* vectors have several benefits; (i) the capacity to hold large genes such as *USH2A*, (ii) they do not integrate into the patient's DNA reducing the risk of introducing unwanted genetic changes, (iii) they do not have any viral components, therefore reducing any immune response, and (iv) long-term gene expression (2 years) has been noted in animal models. We will be treating our human retinal cell model of Usher syndrome to test the safety and effectivity of this non-viral gene therapy. Non-viral *S/MAR* vectors may revolutionise the treatment of inherited retinal disorders by providing a safer and more applicable form of gene therapy.

Another treatment that is closer to clinical trials is the development of a drug treatment that could act on a particular type of mutation, called a "nonsense" mutation, which accounts for around 30 %

“Before we can move to a clinical trial for Usher syndrome, we need to conduct robust natural history studies to understand the disease progression.”

of patients with Usher syndrome. Nonsense mutations are caused by a single letter spelling mistake in a gene that introduces an abnormal stop signal into a gene; this stops normal protein forming, resulting in disease. A new drug called Translarna¹, identified through large drug screens, has the ability to override the abnormal stop signals and restore approximately 20 % of normal protein. We have seen great promise with this drug in the laboratory and we are now planning a clinical trial. Translarna has been given NICE approval for the treatment of Duchenne Muscular Dystrophy², a condition also caused by nonsense mutations. It is taken orally and only mild side effects have been reported in a few patients such as feeling nauseas or transient diarrhoea on starting the drug which resolves. A drug therapy that safely targets nonsense mutations could treat a substantial proportion of patients, in a disease- and gene-independent manner, making the approach both practical and economical.

Before we can move to a clinical trial for Usher syndrome, we need to conduct robust natural history studies to understand the disease progression. This will allow researchers to identify the correct measures to use in a clinical trial that will show a difference if a

treatment is working or not. This may be central vision, colour vision, field of vision or even structural changes within the retina. We are currently running a natural history study for Usher syndrome at Moorfields Eye Hospital, this includes type 1 Usher syndrome caused by nonsense mutations in *MYO7A* and type 2 Usher syndrome caused by the same mutation in the *USH2A* gene. On behalf of all clinical researchers, if there are natural history studies underway or patient discussion groups focussed on your condition, please do volunteer to help. It helps us to understand your disease in great detail, develop new treatments and plan appropriate studies/trials that will ultimately benefit patients.

If you have not received a genetic diagnosis yet and would like to take part in the 100,000 Genome Project, or volunteer for a natural history study mentioned above, please contact mariya.moosajee@moorfields.nhs.uk. Please do not hesitate to make contact if you have a genetic result but do not know the type of mutation, and would like us to check your results.

To watch the "Update on Usher syndrome medical research and new treatments on the horizon," please click on the following link: <https://vimeo.com/238404158>.

¹ www.ptcbio.com/en/pipeline/ataluren-translarna

² <https://www.mda.org/disease/duchenne-muscular-dystrophy>

Conducting Psychotherapy with Individuals with Acquired Deafblindness

Maj Volden

Introduction

In this article I will share my experiences of working as a clinical psychologist for individuals with acquired deafblindness, during a period of almost 20 years. I am interested in how deafblindness may influence the person in a broad sense, also when it comes to psychological challenges. How can the person learn to live with the ongoing challenges in a way that makes it possible to continue being oneself, with fulfilling relationships and activities?

People in general seek psychotherapy to gain emotional and relational changes to increase their quality of life. This will also be the case when deafblind persons seek therapy. This group of patients experiencing feelings of insecurity, lowered self-esteem, grief, anger and anxiety have been seen in therapy (Minor, 1999; Volden 2006). These factors are not specifically connected to deafblindness, but can be caused by all kinds of adversities and strains, including when it comes to deafblind patients. But because deafblindness may interfere with so many functions in life in a negative way, living with deafblindness will almost always be a theme when conducting therapy with these patients.

My experience has taught me that some challenges seem common to most persons in this group. At the same time situational and personal vulnerabilities and strengths, will influence how the challenges are coped with. What will be focused in therapy with each person will be very individual, as with persons without sensory loss.

I am often struck by the resilience of individuals with deafblindness. Most of them will go on with their lives in fulfilling ways, even though there might be periods that require readjustment and support (Ellis & Hodges, 2013).

To my experience focusing on building on strengths, is of utmost importance. At the same time the specific challenges need to be understood and addressed.

Pitfalls

For therapists conducting psychotherapy with deafblind individuals there will be a danger of falling into different pitfalls. There is a danger to focus too heavily on the challenges connected to deafblindness, by attributing all problems to the sensory losses. On the other hand; ignoring the potential negative consequences, could also leave the patient feeling not understood.

The influence of other individual and situational factors on the persons



Maj Volden

“To my experience focusing on building on strengths, is of utmost importance. At the same time the specific challenges need to be understood and addressed.”

psychological health, should also be examined, both when it comes to the person’s vulnerabilities and strengths. Each person will handle challenges in different ways, due to personality factors, degree of social support, values and former experiences.

The theory of specificity

Chronic diseases or disabilities will permanently change the life situation of the individual in specific ways (Haug, 2009). This will be the case whether the person has diabetes, cerebral palsy or dual sensory loss.

To achieve results in supporting the person, the challenges need to be handled both practically and psychologically. The specific challenges of deafblindness are those that can be generated directly from deafblindness, while reactions of helplessness or anxiety can be reactions to all kinds of disabilities and adverse life conditions. These reactions may also be multi-determined, by an interaction between several causal factors.

This perspective differs qualitatively from the psychiatric perspective, by not focusing on mental symptoms and negative feelings in itself, but rather focusing on normal reactions to a specific abnormal and unwanted situation. Emotional reactions are seen as closely related to normal human needs. How a person will adapt to the situation, will be influenced by individual resources, vulnerabilities and factors of resilience.

It is seen as important to describe and handle the specific challenges connected to the specific somatic condition or disability of the person. The therapist meeting a person with diabetes needs to know how the blood-sugar level will influence the patient's general condition and mood. The therapist meeting patients with deafblindness needs to know

how these persons meet obstacles in communication and in the information process due to sensory loss, and be sensitive to how this fact influences the individual in a broad sense.

Psychological challenges linked to deafblindness

The very specific challenge related to deafblindness is that the person to some degree has a restricted access to information and communication. This is the core challenge for deafblind persons, and should be taken care of in a practical way. But it is also important to understand the psychological consequences that may follow.

One psychological consequence of the restricted access to information, is that a deafblind person will have to concentrate very hard in the communication process, as well as in different practical situations including their mobility. In this demanding situation, their stress level will be lowered. The person has to be very alert when orienting indoors and outdoors, moving safely and efficiently (Ellis & Hodges, 2013). This can leave the person more prone to becoming tired and even exhausted. Technical aids, companions, guide dogs and other support methods, can contribute to a less tiring everyday life and less stress, as well as planning activities in a thorough way. This need of predictability can make it harder to participate in spontaneous activities. A certain accepting of this is needed, to avoid frustrations and feelings of loss.

When tired, most people will feel less self-confident

and will more easily become vulnerable to the experience of negative feelings, at least if they don't understand this process.

Tiredness and negative feelings are secondary reactions, not directly connected to deafblindness and will also be influenced by other factors in the life situation, personality traits, somatic health and where you're at in your process to accepting deafblindness.

Persons with acquired deafblindness often tell me that they miss the emotional information that you can get when looking at a person's face. This together with the communication challenges, can result in feeling more insecure, left out, lonely and isolated. These relational challenges can again result in depression in persons vulnerable to this.

If lack of sensory input is not compensated for, the deafblind person could be in danger of being left alone too much with his own thoughts. Sensory input in general triggers new thoughts, memories and will in this way result in a variation in the inner world of a person. Being with others or joining in activities is for most people something that gives life meaning. But these activities and inputs also result in a diverse inner world by the thoughts, feelings, memories and atmosphere they bring about, after the activity is ended. The traces of good experiences will live inside the person when he is alone, vitalizing him and making him feel participating and less prone to feelings of isolation and depression.

Layers in psychotherapy

When a person takes the step to seek psychotherapy, some symptoms or emotional pain will lie ahead. The person will often feel trapped in an unwanted situation where his means to cope are no longer sufficient. The feeling of not understanding fully what is happening to him, is often experienced. There is a need to sort out and understand oneself better.

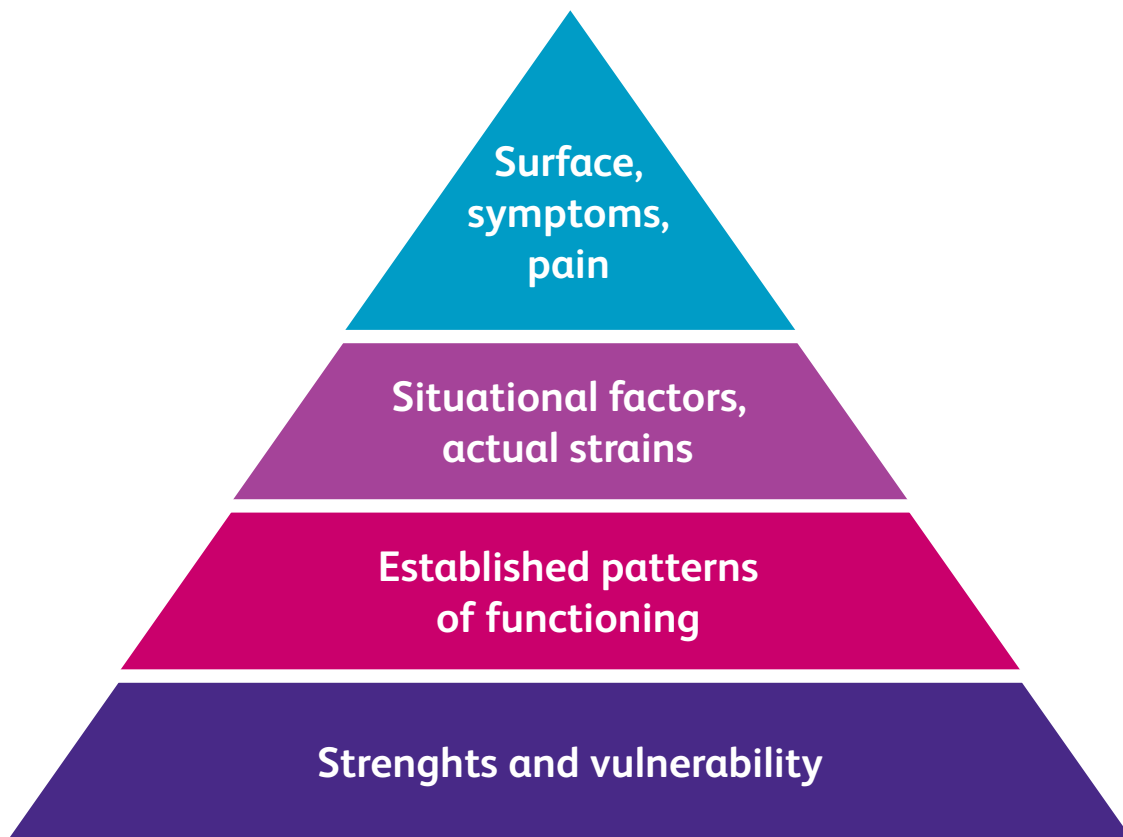
The problems that the patient presents initially, could be closely connected to adverse factors in his actual life situation. If he has problems in his marriage, this could make him feel sad, uneasy or angry. He might also feel exhausted due to a strenuous communication situation at work, or both. Having problems in one area will leave the person with less surplus to handle problems in other areas as well.

By sorting out how the actual situation influence him, it will be easier for the patient to regain self-compassion and energy. In cooperation with the therapist he can discover new ways of problem-solving and making realistic plans. The personality factors and former experiences will always influence how the patient experiences his actual situation. But with some patients working solely with solving the challenges in the actual situation, will be sufficient to reduce or bring symptoms and emotional pain to an end.

For some patients, personality traits and more established patterns of functioning may be a hindrance to find good solutions. If the person is vulnerable and feeling rejected by others, he might give up on others before he get to know them. This will

contribute to his isolation and loneliness. In this situation the patient will have to work on this, to better his social functioning. This can be done through for example mentalization-based or cognitive psychotherapy. By increasing the patients' ability to understand and handle his own and another person's reactions in a more constructive way, can make it easier to accept and relate to others in mutual relationships.

The therapist may also discover fundamental strengths that can be more focused and taken into action, to help the patient cope in a better way. A person who is fundamentally curious and strong-willed, can be supported to join in new activities or develop new skills. This can vitalize him and give new pleasures.



Supportive interventions

Persons with deafblindness starting in psychotherapy relate to deafblindness in different ways for various reasons. Grief reactions and other emotional reactions should be understood and handled. It is also important to get support to develop ways to cope with the “every-day” stress and find ways to get relaxation.

Different patients will be in different phases of acceptance of their deafblindness. For most persons it will be hard to get a diagnosis and get the knowledge that their vision might deteriorate even more. Some patients have gone through a long process towards a greater acceptance of being deafblind. Others may be in a phase where they do not want to focus on deafblindness because it triggers fear and worries about the future. There will be a need of different supports in the different phases, as described by Gullacksen et al., 2011. The therapist ought to be sensitive to this.

Patients will often feel relieved when they gain a better understanding of the relation between their situation and their emotional and behavioural reactions. Getting this understanding, will to my experience, make it easier to set realistic goals and go on with life, despite challenges that will exist on a permanent base.

Some patients may have many negative thoughts about using mobility tools and can have a need to sort out these negative beliefs, to get motivated to use tools. Others find it difficult to talk

with their family, friends and workmates about their needs connected to deafblindness. Getting support to take the step to tell others about their communicational needs can be a useful intervention. The result will often be that others will pay them attention in a more supportive and positive way.

Insight-oriented psychotherapy

As in psychotherapy with other patients it will for many patients be of great importance getting a deeper insight to your own personal development, your vulnerabilities and strengths. Emotional reactions to living with deafblindness, could also trigger memories from other situations that are connected to the same feelings and relational strains. By detecting and processing emotional reactions in

your own personal story, it can get easier to sort out what belongs to the actual situation and what is connected to a history that you cannot change. For most patients understanding your personal history better, will decrease emotional tension and increase self-compassion. The self-blaming will be reduced. The insight can also help the person focus more on realistic problem-solving and less on rumination.

Some patients will need more specialized trauma-therapy, if serious traumas have been a part of their history.

Developing new narratives can also be a part of the therapy process, for example by going from looking at oneself solely as a victim, to looking at oneself as a struggling person, a survivor or just an ordinary person, like everybody else.

“Developing new narratives can also be a part of the therapy process, for example by going from looking at oneself solely as a victim, to looking at oneself as a struggling person, a survivor or just an ordinary person, like everybody else.”

“**Protective resilience factors are not static and can also be strengthened or developed in therapy, by getting support and explore new possibilities to cope.**”

Building on the strengths

In general, when facing illness and major strains, some personal traits will protect one from developing lasting, mental problems. Protective resilience factors are not static and can also be strengthened or developed in therapy, by getting support and explore new possibilities to cope. There will also be more situational resilience factors, that will protect the person, like having a job, a supportive family and access to good services. But here I will concentrate on the more personal factors.

Having self-confidence, being an extrovert and energetic are traits that might protect the individual.

These factors may hold up the motivation to stay active and in touch with others, which again can protect from negative isolation and passivity.

Curiosity and eagerness to learn new things, will point in the same direction. When being curious, the individual will be stay in the information seeking process, even though it is hard. This will again provide a lot of new thoughts and stimulation, filling their mind with thoughts to share with others. The focus will also be less directed inward, which will make the person less vulnerable to get depressed.

The therapist could also contribute in strengthening the person's ability to accept

oneself by recognizing the person he is and the choices he makes. Strengthening the flexibility both by challenging the persons views and his attitudes, could also make the patient less vulnerable.

Having a good working relationship and empathy with the patient is fundamental. A genuine interest in the patient, focusing on their human needs is of crucial importance in all therapeutic work.

For more information, contact Maj Volden (majvol@ous-hf.no), Clinical Psychologist/ Unit Leader for adults, The Norwegian National Unit for Hearing Impairment and Mental Health, Oslo

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Australia

Deafblindness in Higher Education: A Student Perspective

Fremantle, Western Australia

Ben Mcatamney, Ablelink Digital Coordinator, Able Australia¹

The desire to pursue skill development and education at a high level is common to people from all walks of life, including those living with disabilities such as Deafblindness. For Melbourne resident Paola Avila, this desire led her to a challenging yet rewarding experience in vocational training when she undertook to study her Certificate 4 in Training and Assessment.

After immigrating to Australia from Chile at age 3, Paola experienced a mixture of specialist Deaf and mainstream education during her formative years. This exposure to different teaching approaches gave Paola a flexible approach to education that allowed her to overcome the obstacles she encountered when entering a higher education environment.

Paola studied her Training and Assessment Certification (TAC) in an all-Deaf class being taught by Deaf teachers using Australian Sign Language (Auslan). Whilst on the surface this might seem like the most inclusive classroom set up possible, Paola quickly realized that despite the use of her native visual language in the classroom, she was still not totally included on an equal level with other students. “As a Deafblind student it wasn’t easy for me to follow the discussions in a classroom full of Deaf students. I felt it was difficult for me to respond to the student’s feedback, especially in groups because some of them signed very fast and at the same time.” Paola’s experience is one common to many students with a disability and is often referred to as the Illusion of Inclusion. Luckily for Paola a solution was found in the form of Deaf Interpreters.

“I had never thought of having Deaf interpreters,” says Paola. “It made a big difference because they are like my eyes and ears to help me follow and get all the information from both teachers and students.” As well as giving Paola full access to the content and curriculum of the classroom, the use of Deaf interpreters also had a profound impact on Paola’s

sense of self and community membership. Paola continues “This was an empowering moment for me. It allowed me to participate in the class like the other Deaf students and to feel part of the Deaf community.”

The skills Paola was able to learn as well as the empowering inclusion she experienced resulting from this small modification to classroom practices have given her great motivation to take these skills out into the community as an advocate for those living with Deafblindness. “Having completed the course, I am inspired to improve Deafblindness specific programs to train interpreters, teachers, service providers, health workers and community workers. With my TAC qualification I now have the skills and knowledge to help me design and set up special training programs to teach professionals, educators, families and peers to understand Deafblindness and work well using different types of communication and supports that relate to the variety of people present in the Deafblind community.”

For more information, contact Ben Mcatamney (email: Ben.Mcatamany@ableaustralia.org.au)



Ben Mcatamney and Paola Avila

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

DEAFBLIND ONTARIO SERVICES POSITION PAPER

Recognize Deafblindness as a Single Disability: Open Your Eyes and Ears

In early 2017, DeafBlind Ontario Services created a position paper, “Recognize Deafblindness as a single disability: Open Your Eyes and Ears,” to highlight the rights of Canadians who are deafblind within the context of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The convention ratified by Canada in 2010, is an International human rights instrument to promote respect for their inherent dignity, as well as protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms for all persons with disabilities.

The purpose of the paper is to continue to build awareness about the distinct disability of deafblindness within the context of the UNCRPD and mainstream the rights and specialized needs of Canadians who are deafblind or are experiencing age-related dual sensory loss.

The position paper further calls for the following key recommendations:

- Official recognition of deafblindness as a distinct disability with equal rights and opportunities for individuals living with deafblindness in Canada;
- Provision of appropriate lifelong supports of Intervenor Services across Canada;
- Collection of data on the incidence of the distinct disability of deafblindness;
- Recognition of the profession of Intervenor Services (starting with inclusion in the National Occupational Codes classification system); and,
- Accessible environments to ensure that individuals with deafblindness lead a quality life and have every opportunity to fulfill their potential and enjoy independence.

DeafBlind Ontario Services requested feedback from families of the people we support, our Government Relations Committee and Board of Directors before finalizing the position paper.

The organization additionally presented the position paper on a panel, *Discrimination Against Marginalized Groups and Differential Access to Institutions* at the Realizing Rights 2017 conference, June 8–10th in Ottawa. This annual conference organized by the Canadian Association

of Statutory Human Rights Agencies (CASHRA) featured presentations and panel discussions from provincial human rights commissions, staff, lawyers, and advocates from around the world.

Throughout the summer, the organization additionally sought sector wide endorsements of the paper and its recommendations from individuals who are deafblind, as well as from organizations that provide services to individuals who are deafblind or who live with other disabilities, provincially, nationally and internationally. A number of individuals and organizations agreed to include their names and logos as confirmation of their endorsement of the position paper. To read the paper, visit our website www.deafblindontario.com or contact us at k.madho@deafblindontario.com for a copy.

Next steps for the organization include promoting the recommendations in the position paper by sharing it across all levels of government and with the wider disability community.



DeafBlind
ONTARIO SERVICES

“The convention ... is an International human rights instrument to promote respect for their inherent dignity, as well as protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms for all persons with disabilities.”

Canada
continued

Reaching New Heights



Peter strongly holds on high above us at the top of the rock wall; who would have imagined he would make it this far?

Peter is deafblind, had never touched a rock wall and had no concept behind rock climbing. Using his physical strength and navigating through his environment Peter is able to accomplish something those may have viewed as impossible or that which may have been questioned as to why someone who is deafblind is partaking in an activity such as rock climbing.

Not only does rock climbing give Peter the opportunity to use his physical strength and transfer his navigation skills to a new environment, it opens up a whole new level of trust in himself and a

greater level of trust for the intervenors supporting him.

The first time Peter rock climbed, he held on for dear life in fear of falling. However, he put his trust and faith in the intervenor supporting him and allowed her to show him he can let go. After a moment, Peter learned that he could lean back and trust in himself and in those supporting him that he would be okay. From this point on he flourished.

The second time Peter went, he grabbed the rock wall himself and began to pull himself up. Each time thereafter Peter became more and more independent, smelling the wall and using

his head to navigate and feel for where the next hold is. With some prompting from two intervenors, one to help guide his feet until they can go longer reach and one to climb right beside him continuing to guide his hands and feet, Peter reached a new level every time he went, with less prompts needed every time.

Peter made it to the top. He cannot see how high he has climbed though he can feel it on his way down. With one hand holding onto the wall and one hand holding tightly onto the intervenor, Peter feels his way down the rock wall as he is lowered. The feeling of accomplishment is not something that can be seen, heard, or put into words. It is something we imagine is felt inside Peter as he reaches the ground holding tightly onto his intervenor with a smirk on his face.

For more information, contact Susan Manahan (manahan@deafblindontario.com)

“Not only does rock climbing give Peter the opportunity to use his physical strength and transfer his navigation skills to a new environment, it opens up a whole new level of trust in himself and a greater level of trust for the intervenors supporting him.”

Expert Conference on Deafblind Pedagogics in Hannover

More than 150 participants from Germany and four additional countries met for the expert conference in Hannover Germany, May 10–11th 2017. The event was titled: “Not every hat suits every head – encountering persons with deafblindness.” This conference which was organized by Deutsches Taubblindenwerk Gemeinnützige GmbH (DTW Hannover)¹ included representatives Germany, the Netherlands, Austria and Switzerland participating partners in the international network project ‘Professionalization of Pedagogical Concepts’ (PropäK EQUAT)².

The moderator of the conference was Mrs. Gudrun Lemke-Werner, Director of the Hannover Educational Center for Sight, Hearing and Communication. The meeting was opened by the group of drummers from the educational center. The Minister of Education of Lower Saxony, Frauke Heiligenstadt, made the welcoming speech.

The various research presentations outlined the situation of persons with deafblindness from pedagogical, medical and technical perspectives. Parents and other persons concerned with deafblind individuals presented various

perspectives on the lives of these individuals. The participants heard insights about the status of the staff training program that is currently being developed in the context of the EU-funded project. The attendees had the opportunity to attend various workshops on concepts and methodologies for teaching individuals with deafblindness. During the various breaks and evening events the colleagues had opportunities for professional exchanges.

Mrs. Prof. Dr. Marleen Janssen from the University of Groningen³, NL, made the opening presentation. Dr. Janssen is chair of the “Congenital and Early Acquired Deafblindness” program which has for ten years offered a Masters degree in Deafblind Education. In her presentation she addressed important aspects of communication for persons with deafblindness.

Other speakers included Mrs. Dr. Marga Martens (Stichting Koninklijke Kentalis, Sint-Michielsgestel, NL), and Mrs. Christel Skusa, senior teacher and specialist in communication, DTW Hannover. Mrs Skusa demonstrated the value of video analysis to help the teacher interact with a nine-year-old deafblind student.

The newly-developed guide “From social interaction to communication – assessing



Expert conference participants

the communicational status of a person with deafblindness” (published by Edition Bentheim⁴) was demonstrated in Christel Skusa’s workshop.

Through the ten years of the Groningen Masters Program, many masters theses have been produced. Mrs. Mijkje Worm, Psychologist at Bartiméus⁵ Centre of Competence for Deafblindness (Doorn, NL), presented hers’, which focused on the successful communication of persons with deafblindness participating with several conversational partners. “This form of conversation broadens the life of persons with deafblindness”, according to Mrs Worm. Her research showed that these persons with deafblindness communicating with multiple partners participated more actively and for longer periods of time in their conversations.

Mrs. Dr. Nadja Hoegner⁶,

¹ www.taubblindenwerk.de

² EQUAT is a follow up from the ‘PropäK’ project (2012–2014), a network is established among professionals from participating organizations in Europe

³ www.rug.nl. University of Groningen is a small corporate member of DbI

⁴ www.edition-bentheim.de

⁵ www.bartimeus.nl. Bartimeus is a small corporate member of DbI.

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head of services and projects within DTW Hannover, addressed a very different subject: the occupational situation of persons with deafblindness. From her detailed study, Dr. Hoegner pointed out the difficulties this group of people have to locate and keep a position in the workplace. She explained that to improve opportunities in the workplace for these deafblind people, it is necessary to inform potential employers about deafblindness and the assistance these people need in the workplace. Actions that DTW Hannover undertake to realize these requirements were presented in a workshop by several colleagues.

The availability of Technical Aids was also a focal point of the expert conference. A workshop titled: "Using Optical and electronic Aids" was made by Mr. Rolf Behr, Medical Products Consultant, Low Vision International (LVI)⁷, conveying the daily life of two students with deafblindness – one attending an elementary school in Hannover, the other attending

the Hannover Special Education Centre for Hearing – Sight – Communication. Mr. Behr explained that the student with deafblindness in the inclusive program uses a screen reading device with a mobile camera system in the classroom while the student with deafblindness who attends the educational center uses a Braille display during the lessons. One of the students was present at the conference giving insights into his program together with his teacher.

During the conference there were further technical and medical aids demonstrated. One presentation of particular interest was made by Mr. Sebastian Kurzhals, an accredited specialist advisor for the visually impaired from Schroeder Optik (Hamburg)⁸. His presentation featured information about possibilities for individualized adjustment of glasses including information on edge filters.

Another important presentation was that of Mrs. Prof. Dr. Anke Lesinski-Schiedat, Medical Director of Deutsches

HörZentrum Hannover (DHZ)⁹ who lectured on the current state of research in cochlear implantation.

The discussion about the use of medical and technical aids for individuals with deafblindness stressed that interdisciplinary collaboration is essential. To demonstrate this, two colleagues from DTW Hannover, an acoustician and an ophthalmic optician, explained their collaboration in their workshop "Pedagogical assessment and consulting".

Examples of other thought provoking workshops included: A discussion of the problem with understanding challenging behavior demonstrated by individuals with deafblindness and additional disabilities; and How to approach a better understanding of the disability by means of "Re-historing Diagnostics".

What is going to happen to professionalization in the field of deafblindness? Mr. Prof. Dr. Markus Lang, Pedagogics for the Blind and Visually Impaired at University of Education Heidelberg¹⁰,



Workshop with Christel Skusa
(Photo Herbert Kubis)



Professor Markus Lang
(Photo by Peter Putz)



Professor Marleen Janssen
(Photo by Peter Putz)

⁶ Research assistant in the Department of Education and Rehabilitation of Low Vision at the Institute of Rehabilitation Sciences at Humboldt-Universität zu Berlin, Germany, dissertation about stress in individuals with Usher syndrome

⁷ <http://lvi-america.com>

⁸ www.kinderbrillen-hamburg.de

⁹ www.mh-hannover.de/19279.html

India

presented a paper based on various research findings, titled: "Social participation and educational situation of children and youths with deafblindness". The findings Dr. Lang explained has resulted in the development of an additional qualification course at the University titled: "Pedagogics on deafblindness". This course is intended for students who study pedagogics of the blind and visually impaired, hearing impaired and for persons with intellectual and additional impairments.

What is the future for PropäK EQUAT? At the end of the conference Mrs. Christel Skusa spoke about the status of this staff training program which has been funded by the European Union through the Erasmus Project¹¹. The decision about the future of this project will be presented at the next conference which will take place in Schramberg-Heiligenbronn (Germany), February, 2018.

During the conference there was the election of a new executive of the Working group on Deafblindness of the Association for Pedagogics of the Blind and Visually Impaired (Verband für Blinden- und Sehbehindertenpädagogik e.V.)¹²

Editors Note: This article was originally translated by Ulrike Broy, Stiftung St. Franziskus¹³ (Heiligenbronn) and revised by the magazine editor.

Why Deafblindness Research is Necessary in India

Atul Jaiswal¹, Uttam Kumar² and Akhil Paul³

Deficits in Deafblindness research

Worldwide, research on deafblindness is sparse (Dammeyer, 2014; 2015; Danermark & Moller, 2008; Wittich et al, 2012; 2013). It is further limited in the context of the developing world such as India (Paul et al, 2016). Despite having such world-renowned persons with deafblindness as Helen Adams Keller (first deafblind graduate in 1904 in USA) and Haben Girma (Harvard Law School's first deafblind law graduate in 2016 in USA), deafblindness remains an invisible condition and people with deafblindness remain an invisible population in mainstream society.

Likewise, in India, we have Dr. Rajendra Singh Sethi, the first deafblind person in the South Asian countries to obtain a doctorate degree⁴. Though the history of this condition can be traced even before 1880, the development in terms of research and practice specific to this population is still in its infancy stage (Dammeyer, 2015). This invisibility could be attributed to various reasons.

Researchers find it challenging to collect data from people with deafblindness who have significant communication challenges. Furthermore, there

exists no distinct methodology to conduct deafblindness research.

There are variations in terminologies and definitions used to reference this population worldwide owing to the great heterogeneity that characterizes deafblind populations (Ask Larsen & Damen, 2014; Dammeyer, 2015; Wittich et al, 2013).

There is very limited scientific research that directly voices the opinions and perceptions of people with deafblindness themselves. Most research conducted on deafblindness has very often been collected not from persons with deafblindness themselves, but rather through individuals serving as proxies (parents, caregivers, or professionals) attempting to understand the experiences, needs, and concerns of these people with deafblindness.

In cases where research has directly included people with deafblindness, it is very often limited to the concerns of people with acquired deafblindness, rarely exploring the perspectives of persons with congenital deafblindness (Dammeyer, 2015). This scenario is even further unacceptable in the context of such developing nations as India for three



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⁴ The subject of Dr. Sethi's degree was: "The Socio-Economic Problems of the Employed Blind in Bombay" in 1990 (Rehabilitation Council of India, n.d.).

¹⁰ www.ph-heidelberg.de/en/home.html

¹¹ ec.europa.eu/programmes/erasmus-plus/node_en

¹² www.vbs.eu

¹³ www.stiftung-st-franziskus.de

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reasons: (a) a majority of the deafblind population in developing nations belong to the congenital group, as more than 100,000 children are born world-wide each year with Congenital Rubella Syndrome (Sense International, 2017; World Health Organization, 2017); (b) less deafblind specific interventions exists in these same countries (Sense International, 2017), and (c) few research publications are produced from the programs that do exist in these locations (Eide & Ingstad, 2013; Sense International (India), 2014). This scenario marginalizes persons with deafblindness and places them on the fringes of mainstream research and development.

The global research literature on disability is very often dominated by the researchers from the global North (developed world) who very often ignore the lived experience of persons with disabilities in the global South (developing world). Moreover, researchers in disability studies argue that there is “a one-way transfer of ideas and knowledge” from the global North to the global South in disability field (Grech, 2011; Meekosha, 2011, p 668). In a global context, disability research is mainly focused on people with disabilities that are in the majority or who can voice their concerns such as those with physical impairments, and that too, are from developed nations (Chappell, 1998). The mainstream disability literature often discounts the voices of researchers who may not have English as their

first language, and may not recognize the added value to the global disability literature from research from the developing world.

The Sustainable Development Goals (2015)⁵ by the United Nations General Assembly pledge that “no one must be left behind”. There is strong drive towards greater empowerment by the year 2030 for vulnerable individuals including persons with disabilities in the developing world. For those people with complex sensory disabilities (such as deafblindness) who are in a minority position, are usually represented through proxy with their challenges poorly represented and underreported in the literature. Hence, uniqueness of deafblindness remains one of the most under researched conditions reported in the disability research field in India and globally. Significantly more research is warranted to study the unique needs of this unique population (Paul et al, 2016; Dammeyer, 2014; Hersh, 2013; Danermark and Moller, 2008; Murdoch, 2002; Wittich, 2012; 2013; 2016).

Implications of deafblind research deficits

The lack of deafblindness research throughout India and the countries of South Asia pose significant challenges for this unique population. These challenges range from missed diagnoses, limited access to appropriate services, non-recognition and inadequate representation in mainstream research and development. Estimates indicate that there could be more than 500,000

persons with deafblindness in India (Sense International (India), 2016). Paul and colleagues (2016) claim that while the disability is not so rare in India, most children and adults with deafblindness, even in urban India, have not been diagnosed and do not receive the services they require. This lack of diagnostic assessment prevents access to these individuals for early intervention, rehabilitation, and educational programming. This is compounded by the fact that appropriately skilled professionals who can diagnose and provide support services to the deafblind population are very few (Jaiswal & Rizal, 2017; Paul et al, 2016).

This similar problem occurs in many countries (Hersh, 2013), but is especially true in India and the South Asian countries, where there is a lack of awareness about deafblindness among medical professionals. This results in a high level of either under-diagnosing or mis-diagnosing the condition (Paul et al., 2016). In some South Asian countries, even voluntary organizations actively involved in rehabilitation of persons with disabilities are not aware of deafblindness; or if aware they do not have the skill to respond appropriately to their needs. Although there have been some improvements in terms of awareness, people with deafblindness are often just given diagnosis by medical professionals and left on their own to find out about deafblind specific services available (Hersh, 2013), and situation in India is no exception.

⁵ www.un.org/sustainabledevelopment/sustainable-development-goals/

Until December 2016, deafblindness was not recognized as a distinct disability within the disability policies of India, which meant that people with deafblindness had little if any, access to social welfare services available to disabled people in the country. This lack of recognition in national legislation prevents individuals with deafblindness from getting appropriate services (Paul et al, 2016). Although the deafblind specific organizations are delivering needs-based services to these individuals, the lack of awareness and recognition about deafblindness in the country were the key deterrents to support deafblind-specific interventions (Jaiswal & Rizal, 2017; Paul et al., 2016). Moreover, due to the limited funding available to support deafblind specific interventions, organizations working with individuals with deafblindness are very few. All these factors contribute to create barriers to conduct research on deafblindness in India and other South Asian countries.

Deafblind work in India by Sense International India

Sense International India, which completed two decades this year providing comprehensive services to children and adults with deafblindness, works to foster awareness about deafblindness in Indian society (Sense International India, 2017). Through its network of 59 partners across 22 states, Sense India is supporting over 77,500 persons with deafblindness (Sense International (India), 2017). The organization has

succeeded in advocating for the rights of individuals with deafblindness by successfully having deafblindness officially recognized as a distinct disability in 'The Rights of Persons with Disability Act 2016', as well as the state-specific disability policies of the states of Rajasthan, Chhattisgarh, Bihar and Meghalaya (Sense International (India), 2017). Sense International India also played a pivotal role in creating awareness on deafblindness and mobilizing services for persons with deafblindness in Bangladesh, Nepal, and Sri Lanka (Sense International (India), 2017).

In 2017, Sense India set up its research ethics board to ensure that there is a strong emphasis on producing evidence-based high quality scientific research on deafblindness related interventions in India. Sense India is also supporting a doctoral study on understanding the participation experiences of persons with deafblindness in Indian society. Understanding the need for producing deafblind-specific scientific literature, Sense International India is focused on strengthening its three national networks (UDAAN – a network of 194 adults with deafblindness; PRAYAAS – a network of 1167 family members of individuals with deafblindness; and ABHI-PRERNA – a network of 674 educators of individuals with deafblindness) to engage in research and advocacy for the rights of persons with deafblindness to be enshrined in new disability law in India (Sense International (India), 2017). Sense International India firmly believes that research and practice

should go hand in hand to fill the void in deafblind-specific services in India.

Future directions

Although the paucity of research in the deafblind field is challenging, better collaborative research and cooperation could overcome the deficits in deafblindness research (Dammeyer, 2015). Research can be a powerful tool to empower persons with deafblindness and help mainstream their voices. The principles of emancipatory disability research as outlined by Oliver (1992, 1997); Barnes (2002); and Stone & Priestly (1996) may help researchers to: (a) reach out to those individuals with deafblindness who very often excluded from mainstream research, and (b) find solutions to overcome the challenges involved in conducting deafblindness research.

Making participants with deafblindness feel valued by treating them as knowledgeable, providing reasonable accommodations and ample time to build rapport, showing sensitivity and empathetic understanding of their condition, might break the barrier of communication and facilitate their engagement in research. Technology can also be a powerful tool to overcome some of these challenges to facilitate research with this population. Individuals with deafblindness should not be treated as passive recipients of support, but rather given opportunities to become active and contributing members of the community. Research can provide them that platform to engage and make their voices count in decisions that affect their lives.

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Conclusion

Persons with deafblindness are generally invisible within the scientific literature. Research about this population is much needed to ensure their human rights are met and their voices are heard in formulating policies and designing services for them. Research helps to mainstream the voices of persons with deafblindness about themselves, and about the social systems with which they engage on a regular basis. Many researchers acknowledge that more research is warranted to study the unique needs of this under-studied population (Paul et al, 2016; Dammeyer, 2014; Hersh, 2013; Danermark and Moller, 2008; Murdoch, 2004; Wittich, 2013; 2016. India has recently recognized deafblindness as a distinct disability in the newly enacted disability act 'The Rights of Persons with Disabilities Act 2016'. This recognition will act as a large stepping stone in India towards the goal of mainstreaming and empowering persons with deafblindness.

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ANNE SULLIVAN CENTRE NEWS

Movement for Wellbeing with deafblind persons

Since September 2015, Laura Sarah Dowdall has been facilitating a creative dance workshops for the residents of the Anne Sullivan Centre¹ and their key-workers. She combines her skills as a professional dancer, healing yoga and movement facilitator to create customised workshops for people with learning, motor and sensory impairments. She believes that dance should be made accessible to everyone, that it's therapeutic and creative benefits offer great healing, joy and freedom to every dancer.

Each week the resident dancers explore movement games, tasks using sensory props and practice dance choreography with their partner.

The workshops aim to:

- Create a safe space for residents and support staff to feel at ease to explore movement potential within their own body and experience its associated positive benefits.
- Discover new joy and appreciation of the body beyond its purely functional and protective purpose in daily living.
- Encourage increased social interaction amongst the deafblind residents and improved communication between keyworkers and the residents.
- Improve balance, co-ordination, mobility and wellbeing amongst all involved.

The weekly sessions have shown many positive results. Some of which have included: an increase in social participation, active suggestion, ability to 'lead' and creative input by the residents as well as improved muscle tone, balance and confidence.



Laura Dowdall

To find out more about the Anne Sullivan Centres dance program see: www.healingyoga.ie/dance-ability or email: Laura@healingyoga.ie

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¹ Anne Sullivan Centre (www.annesullivan.ie) is a small corporate member of DbI

Ireland continued



Catherine McDonald

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Anne Sullivan Centre Advocacy Working Group

Advocacy is central to the work of the Anne Sullivan Centre. Our aim is to generate momentum for recognition of deafblindness as a distinct condition. We aim to do this by increasing political commitment to the inclusion of the condition of deafblindness in public policy as well as commitment to the mobilization of resources for the provision of deafblind specific supports and services. We will achieve our aims by working in partnership with those who are Deafblind, their family members, carers, service-providers and other interested parties.

“Our aim is to generate momentum for recognition of deafblindness as a distinct condition.”

The Anne Sullivan Centre is supporting people to develop an Advocacy Working Group (AWG). The overall purpose of the AWG is to empower individuals to self-advocate and to provide a platform to guide and co-ordinate the inputs of the Anne Sullivan Foundation in the design and implementation of strategies to increase resources and action with regard to deafblindness in Ireland.

The AWG meets four times a year in Dublin. The group started out with three individuals who are deafblind and five months later, the group is now comprised of two Anne Sullivan Centre employees, seven individuals who are deafblind and two parents of people who are deafblind. The group has been working together over the past number of months to identify and agree on ‘A Vision for Change’. As part of this process, various actions for achieving societal, political and environmental change were suggested by the group. Everyone’s experiences were different to

a certain extent and therefore everyone had different ideas.

One of the members explained the difficulty she has in attending hospital appointments; the receptionist or doctor would call her name and because she had very little hearing or vision she was unaware that someone was calling her name and she would miss her appointment. The group agreed that this is a problem for most individuals who are deafblind and therefore have decided to focus on increasing awareness of deafblindness among health professionals; they plan to get involved in awareness training in hospitals in coming months and are working on strategies that will help hospital personnel to understand the support needs of individuals who are deafblind.

The hope is that the group will eventually lead their own meetings and decide to spend some of their time advocating for their own rights and the rights of other people who are deafblind in communities across Ireland.

Only Mountains Can be Better than Mountains

Russia

During this past September 2017, our organization Deafblind Support Foundation Con-nection¹. organized its first Russian Deafblind Week. We were privileged to host the event in Dagestan, a republic in the southern part of Russia. The participants enjoyed the Northern Caucasus Mountains, swam in caressing waves of the Caspian Sea and became acquainted with national traditions of this amazing Russian region.

During Russian Deafblind Week, 200 deafblind people from all over Russia (from Khabarovsk to Kaliningrad), were beneficiaries of the Foundation. The participants had an interesting but intense program during which everybody could better understand the peculiarities of the region: its history, culture and traditions. Introduction to the national traditions of Dagestan started immediately upon arrival when the guests were welcomed by local singers and treated with national cheese and bread. Lezginka², a national dance of the Lezgins (one of the ethnic groups in the Caucasus), left nobody indifferent. Even totally deafblind people started to dance; it was impossible to resist the energy of music.

“Only mountains can be better than mountains”, sang the great Russian singer-songwriter Vladimir Vysotsky³. That is really so! And even narrow mountain roads made not a single participant afraid. Sulakskiy Canyon is an

enormous natural creation which impressed visitors with its magnificence; such views are forever kept in our memory. The deepest part of the Grand Canyon in Colorado (USA) is 1800 meters; the canyon in Dagestan surpasses its American counterpart by 120 meters. In some parts its mountainsides are almost vertical. Their height is 200–300 meters and in some places, 600–800 meters.

The mountains were quiet in their thoughts. Some of them are reminiscent of heads of old men with wrinkles on their faces; the landslides are like traces of great thoughts and worries. How old are these mountains? Many million years old? Did they notice that a thousand years ago a human settlement was established in the canyon? 1000 years is no more than a minute for a mountain. The aul (the name for a traditional settlement of people living and fortified village in the Caucasus) is located at the very bottom of the gorge where the sun rarely caresses it with its beams. It seems that the sky itself bending forward strives to understand how people live there.

Then there is the ancient city Derbent which is 5000 years old. It's the southernmost city in Russia with many amazing sights. In Derbent every stone is a legend, every wall is a fable, every house has a story! Fifteen centuries have passed since the day Citadel Naryn-Kala was built but today most of the buildings and houses in



the historical part of the city still retain their appearance. In days gone by, Derbent had 15 mosques located throughout every district of the city. The oldest mosque in the territory of the former USSR is the Juma Mosque, built in 880 and still functioning still now for 1260 years. The huge sycamores in the mosque yard, as old as the Juma Mosque, drew everybody's attention.

The Armenian Church built in the beginning of the 19th century and the house-museum of the poet and one of the leaders of the Decembrist revolt in Russia Bestuzhev-Marlinsky⁴, can still be found in Derbent. Some monuments were reconstructed, among them are Khan Palace on the territory of the Citadel, the Christian Church from the 5th century and various fortifications. The city of Derbent which is located on the old Silk Road has retained many historical sights and is very popular with tourists.

The world famous urban settlement Kubachi was also visited by our participants. The road passing through mountains, along the

¹ www.so-edinenie.org. Russia Deafblind Support Fund is a small corporate member of DbI

² https://www.youtube.com/watch?v=JrjNR7hyD_o

³ Vladimir Vysotsky

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

Russia continued

sea, past vineyards and through the city of Varachan (destroyed by the Arabs in the 8th century), isn't easy to navigate, but is incredibly picturesque. It continues past the city of Izberbash (the most comfortable place to live in Russia), along the rocks which reminds one of the face of the famous Russian poet Alexander Pushkin⁵. On the way to Kubachi there was one stop in the settlement of Madzhalis which was founded by the Arabs in the 16th century.

The Persian name for Kubachi is Zerihgaran (Place of Chain Mail Makers). It also had another name – Turkic Ugbug, which means death of people. This was explained by the fact that for centuries different types of weapons have been manufactured there such as chain mail, sabers, daggers, etc. Times have changed and at the beginning of the 20th century local people started to produce new items such as jewelry and exquisite silver tableware. In the very center of that old settlement you can find the

Kubachi Crafts Factory which is famous all over the world. Its history is closely connected with the history of Russia and Dagestan. Of interest in the factory museum where the best art works of famous craftsmen are collected can be found medals from the 1980 Moscow Olympic Games. These days the Kubachi Crafts Factory unites the most skilled jewelers; the production process combines ancient traditions with modern technologies working with precious metal.

As we were in Dagestan we had to visit the hottest place in Russia – the sand dune Sarykourm. At midday in summer the temperature there reaches 60–80° C. The sand dune itself is 3 km wide and 10 km long. While the giant dunes and Sarykourm peaks are capable of moving along the surface; they are in general quite stable. The Shura-Ozen River which flows from the picturesque Capchugay gorge cuts the dune into 2 halves. On that piece of desert can be found over 350 plant types, almost 200 bird species, 3 dozen species of mammals and 2 dozen species of reptiles. One reptile species of wonder is the Mediterranean tortoise (*Testudo graeca*). But the most important thing is that once you find yourself in this area that you immediately get the impression of being in a real desert! While one can see 100-meter high dunes created by wind around you, no sea or adjacent mountains are visible.

For the whole week our participants had a chance to learn the culture and traditions of Dagestan. For example, in the Madzhalis settlement they



Prepared by: Elena Geleskul, Regional Development Program Manager, Deafblind Support Foundation 'Con-nection'. For more information, contact: a.krapukhin@so-edinenie.org

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got to know ancient Dargin customs and traditions. They were invited to a real Dargin wedding as honored guests. During the cooking workshop the participants found out some culinary secrets; sampled and cooked several local dishes, such as: khinkal, chudu, etc.

And the sea! Our participants enjoyed the warm Caspian Sea with its gentle waves for the whole week. We were swimming in the Caspian Sea even when it was a bit stormy. With our Tver deafblind group we invented a way of swimming in the sea: we made a circle or a chain in the water holding each other's hands and all together jumped over the rising waves. It was very funny. "What was more important is that it was safe as there were totally deaf and totally blind swimmers among us", said Aleksandra Nechaeva, Russian Deaf-Blind Week participant.

Russian Deaf-Blind Week finished with an amazing fireworks display; all to be kept forever in each participants' memory.



⁵ https://en.wikipedia.org/wiki/Alexander_Pushkin

Alexander Suvorov's Book

Russia
continued

Alexander Suvorov is deafblind. Losing his vision and hearing in early childhood has made him feel totally separated from the world around him. However, this did not prevent him from graduating from Moscow State University in the 1970s through the framework of the famous Zagorsk experiment¹. Along with three other graduates, Suvorov had the opportunity to work and communicate with prominent Russian psychologists, educators and philosophers. Moreover, he proceeded with his research and later defended his doctoral thesis. He proudly holds the title of professor as he continues his work in the university.

Alexander Suvorov is active in his social life as well. He travels a lot, delivering public lectures around Russia and abroad. He is also an author of books, short life stories and poetry. We did not want to miss the opportunity to convince him to sum up his life experience. The result is Con-nection Foundation's² upcoming publication of his new book "The Meeting of the Universes or Deafblind Aliens in the World of Sight and Hearing".

I first met Prof Suvorov in 2014 when we were seeking contacts with the expert community at the start of our foundation. We were looking forward to meeting all the living participants in the Zagorsk experiment. Before the meeting we had active SMS-exchange with Alexander. I was surprised

to receive his clear-cut instructions – where to come, how to enter the house and use the doorbell together with the mobile phone (so that he might get the vibrations), etc. I didn't have an interpreter and worried about our mode of communication. We managed to find the common language rather quickly. I was first writing on his palm with him answered out loud. Then we proceeded to using the keyboard and the Braille reader typing, which made the dialogue even faster. Since that time, we have become friends and regular interlocutors via email.

I had a dream to publish Suvorov's book! We regarded this book as a real-life encyclopedia of deafblindness written in an easy-to-read, understandable and appealing form. His life had been full of interesting meetings, with a series of ups and downs, but always with a positive attitude towards everything that happened.

Initially the book was supposed to be called 'Typhlosurdopsychology', the Russian word for Psychology of the Deafblind. It was important to make this knowledge available not only to the scientists and university professors, but also to a wide variety of parents with multiple disabled children, relatives of deafblind people and to any person willing to enlarge their knowledge and understanding life's total reality.

As a result, we get a vivid book, filled with thoughts and



Alexander Suvorov

emotions, where each chapter can be read in logical sequence or separately as an independent mini-novel.

Some people will find it interesting to know more about the learning process of persons who are deafblind and about their perceptions of their surroundings. Some will be happy to read about the memories from the Zagorsk experiment that including the trusting and friendly relationships that developed between the students and their teachers. Some will be eager to learn about the pedagogics and the reports from the summer and winter camps where deafblind children integrated with their peers. Others will learn about how their life at home and at work were organized, with the attention to detail about how each person with deafblindness went about overcoming their dependence on relatives and friends.

The book speaks a lot about relationships and communication, similar to a classical novel. One can follow the evolution of the controversial personality Prof Suvorov, as he builds his

¹ <http://www.tandfonline.com/doi/abs/10.1080/10609393.2016.1315274?journalCode=mres20>

² Con-nection Foundation (www.so-edinenie.org) is a small corporate member of DbI.

Russia
continued



Book cover

identity, fights for his respect, while learning tolerance and flexibility. Probably Suvorov's most important message in the book is for parents to change their attitudes towards their disabled child by bringing them up as independent, self-relying individuals, ready for equal partnership, implying an equal responsibility from each side.

This book is very important for our Foundation. Its' publication is meant to raise awareness about a different reality – the world of deafblind people, who are invisible in many countries. This book reveals that through good education and training, the lives of disabled individuals can become full and enriched, like any human being. Alexander Suvorov himself proved an excellent example of this through the power of his talent.

**Dmitry Polikanov, PhD,
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Deafblind Actors Performed the Play 'In Touch' in London

On 14 October 2017 in London (UK), the People's Artist of the Russian Federation Evgeniy Mironov and the British actress Jenny Agutter acted in the international premiere of the play 'In Touch' which was focused on communication with deafblind people in different countries and cultures. Together with Russian and British professional actors, 5-Russian, 1-French and 2-British deafblind actors also took part in the performance.

The performance is based on real life stories of deafblind and professional actors from different countries, told with the help of speech, sign language and dramatic activity. The main lines of the play are stories about two deafblind people: Olga Skorokhodova, the first deafblind woman in Russian science, and Aleksandr Suvorov, the only living deafblind Doctor of psychology and professor. The play was shown with subtitles and audio-description.

"Our main idea was to have absolute equality of all the characters in the play. In the first version of the play all stories about the deafblind people were told by actors who could see and hear. In the second or international version, all participants became storytellers. The play which was staged in London was not identical to the performance shown more than 30 times in Russia. It

reflected changes in the lives of its characters as well as changes in society including changes initiated by this project. The Russian-British version was created by two directors, Ruslan Malikov and Jenny Seley, as well as deafblind actors from both countries. It had an international context, thus interesting to the audience in Great Britain", says the project creative producer Victoria Viollo-Avdeeva.

Two years ago, Victoria went to Great Britain to study Inclusive Theatre and discovered that no one worked with deafblind actors in the UK despite the fact that professional theatre for actors with different abilities had successfully existed for more than 30 years and was a prominent part of British culture.

"It was interesting to me and to Jenny Seley to experience performances with deafblind actors. We understood that such exchanges might give us both something new and yet unknown. So, we started negotiations", continued Victoria Viollo-Avdeeva. Last year she thought about staging the performance in the National Theater of Great Britain.

"It was the first theatre which doors I had knocked on; and they were opened! Long before that idea had come to my mind to create a new version of the play, I had seen the difference in the way that deafblind actors



Russia
continued



In Touch at the National Theatre (Photography by Patrick Baldwin)

performed in the first version and what actors they had become after several theatre plays combined with lessons at theatre school. They had changed; the whole team had changed. This new version is a great way to demonstrate a high quality social project. Stories of these deafblind actors from Russia and Great Britain show that such projects are necessary because people with dual visual and hearing impairments are the least visible to the society”, Victoria Viollo-Avdeeva emphasized.

The first version of the performance was shown in Moscow on the stage of the State Theatre of Nations in April of 2015. Since the premiere, the play has been performed more than 30 times, with many outstanding Russian actors taking part,

among them Evgeniy Mironov, Ingeborga Dapkunaite, Anatoliy Beliy, Alisa Freindlih, Igor Kostalevskiy, Evgeniy Tsyganov. The play was nominated for Golden Mask Theatre Award.

The performance in London was organized by the Center for Creative Projects for Inclusion and the Theater Company Graeae, with participation of the British Council, the Deaf-Blind Support Foundation Connection and Sberbank of Russia. The project partners were State Theatre of Nations (Moscow), National Theater of Great Britain (London), British Embassy in Russia, Museum of Russian Impressionism, Azimut Hotel Chain and Cultural Center ZIL.

Now the performance will be going to Paris where it will be shown in UNESCO.



Prepared by:
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Sweden

The National Resource Centre for Deafblindness in Sweden

The National Resource Centre for Deafblindness¹ has acted under the Mo Gård foundation² since 2003, and acts under the National Swedish Board of Health and Welfare since 2013. The primary task of the knowledge center is to offer different kinds of expert support about deafblindness to various responsible authorities and sectors, both in terms of assessment and diagnose habilitation and rehabilitation. The aim is to develop and spread information about deafblindness in different forms and in different contexts. Another aim is to outline long-term strategies in order to create sustainable support for people with congenital, as well as acquired, deafblindness, of all ages and in the whole country. It is of great importance that research and development results are observed and made accessible. For the present being, there are 8 employees and around 15 consultants working with Nkcdb. More information about the activities is available at www.nkcdb.se.

Mo Gård has a long tradition and great experience in working with people who communicate with sign language, or who use other alternative methods of communication due to deafness, hearing impairment and deafblindness. It is quite common to have a combination of different functional impairments. Therefore, great importance

is attached to the communicative and physical environment.

The National Resource Centre for Deafblindness (NKADB) has signed a new agreement with the National Board of Health and Welfare (Socialstyrelsen)³ for the period of 2017–2022. The commission includes the following areas:

- Expert support (medical issues, identification of deafblindness, habilitation and rehabilitation, technical aids, interpretation related issues, legal issues, etc.)
- Gathering, developing, and spreading information about deafblindness
- Working to systematically develop methods within the deafblindness area
- Courses and trainings
- User co-operation

The awareness around deafblind issues has increased in the country during the last few years, and more and more people reach out to us for specialist support, or to participate in different activities that we arrange. NKADB has a network of contact persons all over the country. Their task is to gather information regarding deafblindness and sharing information from us further out into their organizations. We offer basic courses regularly. There is an increased wish to participate in distance education and lectures like e-learning. A number of articles have been

published on the website during the years, several focusing on current research. Our research overview was updated in March 2017. Since the mid 90's, there has been a Swedish National Expert Team for diagnosing persons with deafblindness. At that time, the situation in the different county councils regarding diagnosing deafblindness was very limited, and over the years, the team has contributed to many diagnoses, some of which were very rare. A diagnosis is important to receive the right help and support. It is stated in the new agreement with The National Board of Health and Welfare (Socialstyrelsen) that it is the responsibility of the healthcare system to diagnose people, and that NKADB instead should offer expert support in analyzing, diagnosing and thus creating the right conditions for the county councils to organize the support for people with deafblindness.

During the years 2013–2016, ICT has been a highly prioritized area, to which we have set aside special resources. This work is now a part of our regular expert support, and an expert group around technical aids and ICT has been established. This is an important area, and we will continue to develop it in the coming years. Another prioritized area is to continue the work with identifying deafblindness among children and we see a great need to

¹ The Swedish Resource Centre for Deafblindness (www.nkcdb.se) is a small corporate member of DbI

² Mo Gard (<https://www.mogard.se>) is a large corporate member of DbI

³ www.socialstyrelsen.se/english

secure a national strategy, to ensure that children have adequate vision and hearing before any kind of habilitation work is initiated.

New areas of work are being planned. One is to produce a knowledge based habilitation program for children and youth with deafblindness. It will be carried out in co-operation with the Association of the Swedish Deafblind (FSDB)⁴, parents, teenagers, habilitation managers, visual managers, hearing managers, and staff within different activities. The second area we focus on is elderly people with a combined visual and hearing impairment, and we will work out a guide for support, a simple handbook with advice and accompanying distance training. There is also a great request for strategies for concrete work with physical and mental ill-health from both users and professionals, also a prioritized area.

Professionals and scientists have a general and systematic

knowledge of deafblindness, but we can only find the personal, individual knowledge of how it feels to live with deafblindness within the individual and his or her family and relatives. Our ambition is to have a continuous knowledge transfer between, on the one hand, professionals, scientists, and, on the other hand, the people living with deafblindness and their family and relatives. Therefore, a close co-operation with the FSDB and its sections is very important to us. To raise the bar at NKADB when it comes to being able to use evidence based support and to strengthen the connection between research and practice, we have employed an R&D coordinator.

I am Head of Operations at the National Resource Centre for Deafblindness (NKADB) in Sweden. Before NKADB I worked in the south of Sweden, in the region of Skane, with different types of tasks and areas. I started

1982. For many years I worked with rehabilitation for people with hearing impairment. After that I started a project building up a regional resource theme for Deaf people. And then I continued to build a similar team for people with deafblindness. That was a very short and brief presentation. Since 2011 I am responsible for the National Resource Centre for Deafblindness. A mission that I love and who engages me a lot. And I have a great team of employees and consultants around me.

During the last years, great emphasis has been put on achieving long term and sustainable strategies to avoid the knowledge being too linked to one person or one place. A great deal remains to be done and we hope that the development in the country at present will continue, so that people with deafblindness and their close ones can have good, fair, and equal support from society.

**Sweden
continued**



For further information, please subscribe to the website: www.nkadb.se and follow us on Facebook.

**Lena Göransson,
Head of Operations,
NKADB**

⁴ www.fsd.org

Unique Swedish Overview About Research in the Field of Deafblindness

Moa Wahlqvist

It was Lena Göransson, Head of Operations at the Swedish National Resource Center for Deafblindness¹, who had first taken the initiative to assemble published research information from the field of deafblindness. According to

Lena: “My ambition was to have an ongoing knowledge transfer among scientists, professionals and people with deafblindness and their relatives. I believe close co-operation is very important.”

Claes Möller, from the Audiological Research Center

at the University Hospital in Örebro², as well as other researchers from Örebro University³, have been also involved with this initiative from the very beginning. According to Dr. Moller: “This research overview is important to the entire field. Researchers

¹ The Swedish National Resource Center for Deafblindness (www.nkadb.se) is a large corporate member of DbI.

² <https://www.regionorebrolan.se/audf/en>

³ <https://www.oru.se/english>

**Sweden
continued**

can find what they need in scientific databases, but this is not the case for professionals, clinicians or other persons interested in the field”.

I have taken on this responsibility now to keep the research database updated, a job that I do together with the extremely skilled librarian Margareta Landin.

So, what is so special about this database we have put together in Sweden? I suggest two main reasons:

It is the only database in the world that systematically collects scientific articles that have been published about deafblindness.

This database gives the possibility to search, in a user-friendly manner, scientific articles of all kinds, from those focusing on specific diagnoses to those of general areas of interest.

A point worth noting is that all search words in the data base are in English. This is because the articles are written in English, making the database useful for anyone internationally.

This work started in 2013. All the articles in the data base have been collected through systematic searches of nine scientific databases up to March

2017. Currently it contains over 3,500 articles related to deafblindness. This overview will be updated once a year.

The data base has been organized into 17 search categories which allows the researcher or professional an easier opportunity to narrow their search to locate publications in such areas as assessments, genetics, diagnostics, cognition, etc. The categories are shown in the figure below.

Through this research overview, professionals and researchers are now able to get a picture of the totality of scientific articles published within those 17 specific interest areas of deafblindness. Some of the articles can be accessed online, but not all due to copyright reasons.

The nine scientific databases that have been searched to locate the scientific articles (examples, PubMed, PsychInfo, CINAHL) only had articles that were published in scientific journals. It is worth noting a limitation in the data base in that not all deafblindness related research are published in these journals.

We are now searching and itemizing other deafblindness

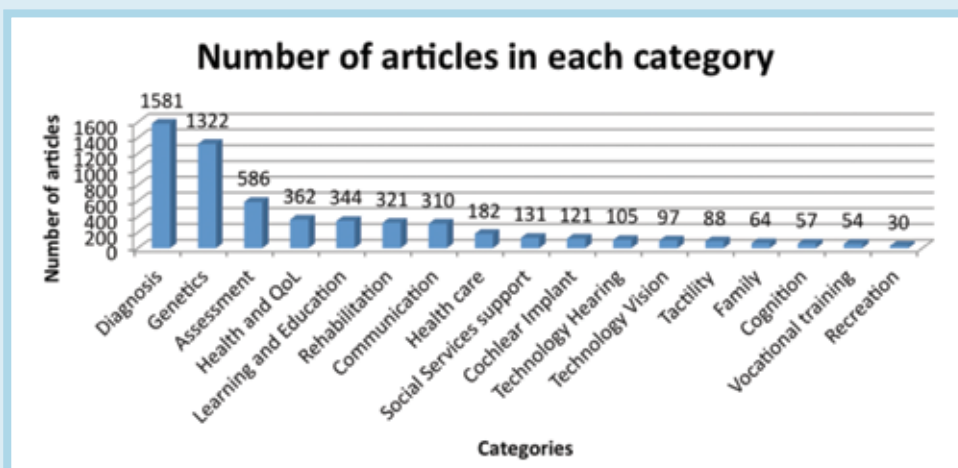
related research articles not published in scientific journals but found in what is called the ‘grey’ literature. We hope to include them eventually in some type of registry.

The diagram below shows the categories and number of scientific articles found in each category. It is obvious in the figure that the number of articles is weighted to the categories of diagnosis and genetics, while few are published in the areas of tactility and cognition. Perhaps this overview could be an inspiration for research in these underactive areas. Note that some of the articles are found in more than one category.

The National Resource Center for Deafblindness Research Overview is located using the following link: <http://nkcdb.se/forskning-och-utveckling/forskningsdatabasen/>



For more information contact Moa Wahlqvist, PhD (moa.wahlqvist@nkcdb.se). Moa is Disability Science Coordinator at the National Resource Center for Deafblindness and Researcher at the Audiological Research Center in Örebro.



WANTED!

Good practice and examples

Our Research overview is developed in order to help the whole deafblind community to get access to scientific work about deafblindness.

Now we want to find other projects, reports, books and written material in the field.

There is a huge need for evidence based practice. Therefore we search for the “grey literature”. Good work, that hasn’t been presented in a scientific context, but still is valuable - for congenital as well as acquired deafblindness.

At this point we are mainly interested in the areas of

- Communication and interaction
- Tactility
- Orientation and mobility

Our aim is to create a register that will be available for everyone on our website, www.nkcdb.se

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DbI Network of the Americas Conference

APRIL 15–18, 2018 / Cape Cod, Massachusetts / Resort and Conference Center at Hyannis



Deafblind International and Perkins School for the Blind are excited to host the first-ever DbI Network of the Americas Conference. The conference promises to be an exciting opportunity to learn, share and reflect with colleagues in the field of deafblindness from North America, Central America, South America and the Caribbean. Of course, the rest of the world is most welcome to join us to enhance the richness of the exchanges and learning.

The venue is within walking distance of the sea as well as Main St. Hyannis. It will provide a truly relaxed atmosphere for the conference and for enjoyable after hours fun!

Partnerships for lifelong learning

The conference theme – Partnerships for lifelong has meaning to all of us, no matter what our role. By partnering as educators, service providers, consumers, policymakers, advocates and family members, together we can offer a lifelong array of support for the deafblind community – spanning from early intervention and K–12 education to programs, services and networks for adults and families.

The following is a peak into the program, but please visit our website at www.dbiamericas.org for the latest updates

CONFERENCE PROGRAM

Sunday, April 15

Conference Registration runs throughout the day. The official opening of the conference begins at 1PM, which includes Words of Welcome followed by: The Keynote presentation by **Dr. Anthony Lake**, Executive Director of UNICEF. An array of workshop sessions completes the afternoon. A Welcome Reception will be held following the afternoon session co-hosted by Perkins International and the National Family Association for Deaf-Blind (NFADB).

Monday, April 16

The theme of the day is *Family Partnerships*; Moderator: **Clara**

Berg, President, NFADB. Plenary Speaker: **Edward Bosso** with a discussion panel on this topic to follow. The rest of the day includes workshop sessions, discussion forums. The evening events include a comedy show by Rene Pellerin, Deafblind Comedian extraordinaire!

Tuesday, April 17

The theme of the day is *Inclusive Societies*. Moderator: **Carolyn Monaco**, President, Canadian Deafblind Association Plenary Speaker: **George Stern** with a discussion panel on this topic to follow. The rest of the day includes workshops, poster presentations, a research update panel moderated by **Dr. Susan Bruce**, followed by

focus group discussions. Evening Activities include Salsa Dancing with **Kerry Thompson**, Deafblind Activist and dancer!.

Wednesday, April 18

The theme of the day is *Measuring Success*. Moderator: Dr. Andrew Fisher, Executive Director, Lavelle Fund Plenary Speaker: **Maurice Belote** with a discussion panel on this topic to follow. These presentations will be followed by workshops; ending with a discussion: What We've Learned and What is Next! Reflections and Challenges for the Future. An evening awards banquet and closing ceremony will bring this event to a close.

Check out the conference website for registration information: Perkins.org/DBIAmerica

Please note that the date for early bird registration fees has passed and registrations close February 28, 2018

Contact the resort directly (www.capecodresortandconferencecenter.com) to reserve your accommodations but hurry, only a few rooms remain!

THE Spirit OF INTERVENORS:



Make a wave
from coast to coast

June 6-7, 2018 🍁 Mississauga, Ontario

Save the Date!

2018 Intervenor Symposium "The Spirit of Intervenor: Make a Wave from Coast to Coast"

June 6-7, 2018
Corporate Event Centre at CHSI
Mississauga, Ontario

Join us!

The Deafblind Network of Ontario (DBNO) is pleased to present the 8th Intervenor Symposium "The Spirit of Intervenor: Make a Wave from Coast to Coast", set to coincide with National Deafblind Awareness Month (NDBAM). This Symposium will provide an opportunity for intervenors, supervisors/managers, and professionals in the field of deafblindness, rehabilitation, and education to gather together to network, collaborate, and learn. We hope you will join us and Make a Wave from Coast to Coast with the Spirit of Intervenor!

Please stay tuned for further details! For future information about the 2018 Intervenor Symposium, please visit: <http://www.dbco.ca>

For additional information or questions, please contact the Conference Co-Chairs: Josie Quinn at: j.quinn@deafblindontario.com or Lessette Morales at: lmorales@chkc.org



DEAFBLIND SUPPORT FOUNDATION 'SO-EDINENIE'
ANNOUNCES INTERNATIONAL CONFERENCE

An International Conference on Deafblindness Titled 'Evolution of Deafblindness and What Follows'

Is planned for Moscow, Russia, April 3–4, 2018

The DeafBlind Support Foundation 'So-edinenie' (Connection) is planning a conference on deafblindness in collaboration with the DeafBlind Support Resource Centre 'Yaseneva Polyana' to be held in Moscow, Russia, April 3–4, 2018

KEY TOPICS OF THE CONFERENCE

- Studies of the current deafblind population
- Causes of deafblindness and changing trends
- Discussion about the current methods of medical treatment to reduce the disabling impacts of visual and auditory impairments coupled with cerebral palsy
- Successes of modern assistive devices and rehabilitation technologies for people with multiple disabilities
- Psychological and pedagogical rehabilitation aspects related to the use of hi-tech medical technology
- Discussion on ways to manage severe multiple disabilities as a result of prematurity
- Modern approaches to the detection, treatment and training of individuals with rare genetic syndromes and inherited complex disorders
- Modern training for specialists working with children having complex sensory and multiple disabilities
- Difficulties training psychologists to help youth and adults with acquired deaf-blindness and other types of complex disabilities
- The disabled person and their challenges in the modern world

To participate in the Conference, registration is required through the Conference website via the link <http://nauka.so-edinenie.org/en.html>. Participants must mark on the form the topics they would like to participate

A registration fee is not required if registering before March 23, 2018. However, participants are required to pay 1,000 rubles for a conference package which includes a USB-flash containing the Conference materials and Certificate of Participation.

If registering after March 23, 2018, the cost for registration and the participation package will be 5,000 rubles. The deadline for submitting abstracts is February 5, 2018.

The Organizing committee reserves the right to select participants according to the topic areas of the conference. Rejected applications will not be notified.

CONTACTS

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Discover Deafblindness Down Under

Able Australia has a long association with Deafblind International and cordially invites worldwide colleagues to join us at this prestigious conference.

You'll hear from a wide range of International and Australian-based guest speakers and discover the latest technologies, research and programs that are helping to empower the deafblind community.

Date – 12 - 16 August 2019

Venue – Surfers Paradise Marriot Resort & Spa
158 Ferny Ave, Surfers Paradise QLD 4217

For more information

dbi2019@ableaustralia.org.au
www.ableaustralia.org.au/dbi2019
www.facebook.com/ableaus



Action Research in Deafblindness Series

Article #6: Dissemination of Findings from Action Research Studies in Deafblindness

Susan M. Bruce



This is the sixth and final article in the Action Research Series. The purpose of this article is to address dissemination of action research findings. Researchers have an ethical obligation to share what they have learned because not only have they invested time and effort in the study, but the participants have as well. So, dissemination can be regarded as one way of respecting the contributions of the participants and those who may have consented on their behalf. Through dissemination we share what has been learned with others for the purpose of expanding what is known in the field of deafblindness and to improve our practices with individuals who are deafblind.

Researchers must consider who they want to share their action research findings with and how best to reach that desired audience. Options include informal sharing with colleagues, formal presentations at faculty or staff meetings, presentations at conferences (local, state, regional, national, or international), formal research reports, posting written documents on a website, non-peer reviewed article(s), or peer-reviewed article(s).

Whatever you choose as your dissemination outlet consider your audience and what they may hope to learn from your study. While we always share key findings, it may be equally important to share findings that were surprising. So, when we anticipate a finding that did not occur or when something occurs that we did not anticipate these are surprises that audiences will find interesting. Whether giving an oral presentation or writing an article, your practical experience, reflections, and actions must be communicated. Sharing what you learned is as important as sharing findings about your students or adult consumers.

Oral Forms of Dissemination

You may decide to present your findings orally, either informally or through a formal presentation. Here is a typical structure for a formal oral presentation that

you might share with your colleagues or at a conference:

Typical Structure for Oral Presentations of Your Action Research Study

- Information about your background (to support your reader to understand how your experiences shaped the study)
- Information about the context of your action research study (selection of research topic, setting, timing of the study)
- The aims of your action research study
- Describe your action research plan (the actions you took to accomplish your aims)
- Describe the data you collected
- Share how you analyzed your data
- What did you learn from the data? (This may include what you learned about yourself and your work.)
- What actions were taken in response to data? What were your action research cycles?
- Future research plans
- Questions/answers (Bruce, 2010; Johnson, 2008; Mertler, 2009)

Some conferences that may be appropriate for dissemination of your action research include:

- *Deafblind International (DbI) World Conference.*
- *Deafblind International (DbI) Regional Conferences.*

- *Council for Exceptional Children (CEC)* (national and state conferences)
- *Association for the Education and Rehabilitation of the Blind and Visually Impaired (AER)* (national, state or regional conferences)
- *TASH*

Written Forms of Dissemination

University researchers are accustomed to the requirement of writing about their research and this is considered part of their typical workload. It is far more difficult for practitioners to find the time to write about their research. Mills (2011) presents several good arguments for the importance of practitioners writing about their research including: to clarify their own meanings, to contribute professional knowledge, and to validate hard work through sharing information and products.

Reading action research reports and articles will support you to write about your own findings. You may find examples of writings about action research studies in Pine (2009) and Bruce and Pine (2010). You may also review journal articles about action research articles that are specific to children and adults who are deafblind (such as Bruce & Parker, 2012; Bruce, Zatta, Gavin, & Stelzer, 2016; and Damen, Janssen, Ruijsenaars, & Schuengel, 2015).

you write a formal research report for your organization or for a funder, you will find Mertler's (2017) chapter on this topic to very helpful. Mertler provides guidelines on titles, voice, tense, language, and formatting. He also provides tips for the novice professional writer, websites to support writers, and links to actual action research reports. Mills (2011) also provides a chapter that includes an outline for an action research report, and writing tips.

You may want to submit your article to an organization with a website that includes content in deafblindness. Examples include the *National Center on Deaf-Blindness* (NCBD), *Perkins School for the Blind*, and state deafblind project websites.

You may prefer to write an article for publication, either non peer-reviewed or peer-reviewed. It is important to first become familiar with the journal options. You will want to read the author's guidelines of the journals before selecting the most appropriate to your work. Be sure to consider the different types of articles that a particular journal allows (such as the research report format offered by the *Journal of Visual Impairment & Blindness*). Before you begin writing your article, become familiar with the writing conventions of the *American Psychological Association* (APA, the required style for most professional journals). Here is a typical structure for a research article:

Typical Structure for Writing Articles about your Action Research Study

- Abstract (summary of key ideas and results)
- Introduction of the topic of your action research study (including your research topic and research question(s).
- Review of the literature that addresses your research topic
- Methodology (design of research, data sources, how you collected your data, how you analyzed and interpreted your data)
- Results/Findings
- Discussion (including limitations). If your study is qualitative, you may want to combine results and discussion in one section.
- Conclusion
- References

The following journals are among those that have published articles about deafblindness:

- *Journal of Visual Impairment and Blindness*
- *British Journal of Visual Impairment*
- *American Annals of the Deaf*
- *Journal of Deafblind Studies on Communication*
- *Scandinavian Journal of Disability Research*
- *International Journal of Disability, Development, and Education*
- *Journal of Deaf Studies and Deaf Education*
- *DbI Review*
- *Visual Impairment and Deafblind Education Quarterly*
- *Teaching Exceptional Children*

Dissemination allows action researchers to share what they have learned about practices in deafblindness while contributing to the literature. In a field with very few active university researchers, there is a need to prepare practitioners to conduct action research studies and to support practitioners to disseminate the results of their hard work.

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Synopsis of a Technical Meeting of International Partners Held in Geneva to Discuss the Structure of the Global Report

On 13 September 2017, Executive Board Members of the World Federation of the DeafBlind¹, as well as representatives from Sense International², the World Health Organisation (WHO)³, Office of the High Commissioner for Human Rights (OHCHR)⁴, and researchers from the London School of Hygiene & Tropical Diseases⁵, and staff of the International Disability Alliance (IDA)⁶ Secretariat met for the first time in Geneva for a technical meeting to discuss the provisional structure of the Global Report that will be presented during the World Federation of the DeafBlind General Assembly in Benidorm, Spain 2018.



Representatives from the Asian, Latin American, European, and African offices of the World Federation of the Deafblind attended the event, which gave to participants the chance to address their main concerns and issues directly to the UN Agencies and others. The representatives provided information regarding the specific situations and violations that persons with deafblindness face in different countries, in order to find together how to better collaborate in the future to solve these issues.

The meeting was opened by the World Federation of the DeafBlind President, Mr. Geir Jensen and chaired by Alexandre Côte of the IDA Secretariat. During the meeting, existing tools for disability assessment and existing researches on deafblindness were presented and clarified in detail. Alarcos Cieza, Coordinator on Disability and Rehabilitation at WHO, made a presentation on the WHO classifications that are used by the health systems, in order to address issues and suggestions related to those tools both in the Global Report and in the reports on vision and hearing that the WHO is planning to produce. Alarcos also invited the WFDB representative

to work more closely with the WHO on these topics and on the reports.

Sense International Advocacy & Policy Manager, Bailey Grey, proposed policy solutions and interventions that were seen as useful for empowering persons with deafblindness, based on the experience of Sense International. Bailey also presented practical examples, such as Sense International's work in Peru, where despite the existence of the legislation providing a right to a guide interpreter for accessing services, the guide interpreter does not exist as an official profession. As such, Sense International is working with the Ministry of Education to deliver live and online courses.

OHCHR Human Rights and Disability Advisor, Facundo Chavez Penillas, presented the human rights approach of the rights of persons with disabilities with particular focus to persons with deafblindness on different levels, in order to propose ways to improve their advocacy. Facundo also suggested to identify priorities regarding the actual situation of the rights of persons with deafblindness, in order to be more effective in drafting the Global Report.

IDA Senior Human Rights Advisor, Tchaurea Fleury

¹ The World Federation of the Deafblind (www.wfdb.eu) is a partner organization with DbI

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

³ www.who.int

⁴ www.ohchr.org

⁵ <https://www.lshtm.ac.uk>

⁶ www.internationaldisabilityalliance.org

presented the opportunities of the UN mechanisms, including the Special Procedures and particularly the importance of the Special Rapporteur on the Rights of Persons with Disabilities as pivotal steps for the advocacy of persons with deafblindness at a global level. Tchaurea underlined that the collaboration of the global community of persons with deafblindness is key for the representation and to raise the issue of the constituency in all mechanisms.

IDA remains committed to working with persons with deafblindness, and will continue to raise the profile of all constituencies it represents.

About the Global Report

With the adoption of the Agenda 2030, attention has been paid to leaving no one behind. Persons with disabilities through intensive advocacy have succeeded to break their invisibility in the Millenium Development Goals (MDGs) to be included in the Sustainable Development Goals. However, persons with disabilities are not a homogenous group and some constituencies such as persons with deafblindness are very often much more marginalised.

The multiple barriers that they faced such as lack of access to support services, accessible information and assistive devices makes it very difficult to even structure themselves in strong advocacy group to voice their issues. They are often marginalised even within the disability movement and do not get a chance to engage in political participation and public life to claim their rights.

Experiences of World Federation of the DeafBlind (WFDB) and the International Disability Alliance (IDA) over the 10 years of work on the implementation and monitoring of the Convention on the Rights of Persons with

Disabilities have shown that there is very little attention paid by national and International stakeholders on the issues of persons with deafblindness. This is both the results and the cause of the general lack of knowledge of the diversity of issues and specific inclusion requirements of persons acquired or congenital deafblindness.

WFDB as well as its members such as the African Deaf Blind Union have succeeded progressively to engage with the broader disability movement to amplify their message within IDA as well as the European Disability Forum, or more recently African Disability Forum or indeed Sense international within the IDDC.

Few elements show that even among the disability specific work persons with deafblindness are marginalised. There are only 7 references to persons with deafblindness in the 2011 world report on disability, 10 times more references to persons who are deaf or persons who are blind. There have been only 6 specific references to persons with deafblindness in the CRPD concluding observation of 40 countries review up to December 2016 (20 times less than for deaf persons or blind persons).

To raise the profile of issues of persons with deafblindness, there is a critical need of an evidence based global report on situation and rights of persons with deafblindness that would become both a reference for CRPD and SDGs implementation. Such report

would also be WFDB contribution to the 2020 SDGs baseline. It is planned to produce a follow up report in 2025 to measure progress.

Such reference global report is critical to build common ground and understanding across regional and global disability, development and human rights stakeholders. WFDB will use the process of development of the report to mobilise both WFDB members, their allies as well as the UN agencies. The process will be fully consultative, including via a survey, to ensure strong ownership by WFDB members.

The report will be built on evidence gathered by researchers of the International Center for Evidence in Disability London School of Hygiene and Tropical Medicine (ICED-LSHTM). While the focus of data collection by WFDB and partners will be on lower income countries. The Deafblind international European conference in September 2017 should provide a great overview of the situation in higher income countries.

As a key milestone in the development of the global report, an expert meeting will also be organized in September in Geneva both to mobilize and to gather contributions of different NGOs and UN agencies including WHO, OHCHR, ILO and the Special Rapporteur on the rights of persons with disabilities among others.

Prepared by Staff from the International Disability Alliance

“IDA remains committed to working with persons with deafblindness, and will continue to raise the profile of all constituencies it represents.”

The World Federation of The Deafblind and its Role in the Development of Persons with Deafblindness Around the World

Master Sonia Margarita Villacrés Mejía, Ecuador, WFDB Vice President

First let me say that the World Federation of The Deafblind (WFDB) is a young, active nonprofit organization that does not depend on any government support in its work to advocate for persons with deafblindness.

Created in New Zealand in 2001, the organization's main goal is to promote the Rights of Persons with Deafblindness all over the world through organizing and supporting equal opportunities for international groups of these individuals. The process for this was to develop an international mechanism to represent this marginalized population at a level similar to other international organizations, such as United Nations. Thanks to the cooperation among organizations that work for the diversity of persons with disabilities, WFDB has now become part of International Disability Alliance (IDA)¹.

I still remember the intense amount of work we did participating in developing the draft of the Convention of the Rights of Persons with Disabilities (CRPD). Even before we became a legal organization, we were part of many working sessions where we constantly spoke out about the existence of persons with deafblindness all over the world. We reminded others that we are a marginalized minority, desperately requiring all levels of services; services that are different from those required by persons with blindness or deafness.

We have obtained the legal recognition from the Norwegian Government, meaning that we are

a legal organization that has the duties and rights to work globally as the voice of persons with deafblindness. WFDB consists of 75 national and associated member organizations from 62 different countries from all corners of the world. The organization is governed by an Executive Council (EC) made up of 10 deafblind EC members; 4 officers (President, Vice President, Secretary General, Treasurer) and 6 regional representatives (Africa, Asia, Europe, Latin America, North America and The Pacific).

The work in the first years focused on organizing persons with deafblindness around the world, letting them know that we were not alone, and that we were collaborating with other organizations to develop our own equality. We continue to do that, because it is not easy for persons with deafblindness to create associations based on their beliefs and traditions, because some persons with deafblindness do not know their rights.

Still today many persons with deafblindness are still living in institutions primarily established for the blind, the deaf, the multiple disabled or for persons with intellectual disabilities. This continues because these facilities still do not know that deafblindness is a unique disability. Worldwide today we are much better organized; our message and goals are clear about what we are trying to achieve.

I'm pleased also to report that we now have three regional

federations: Latin America, Africa and the Europe. Each federation has national members who represent persons with deafblindness in each country. However, this does not mean that all persons with deafblindness in those regions are totally represented. These regions are large and the numbers of these marginalized people in each region are small, meaning communication is very difficult.

We understand that many of these persons with disabilities are integrated and supported by various national organizations in those regions trying to improve their quality of life. This in no way means that we have solved all the personal issues and needs for all those individuals identified that we represent. At least we have tried to support them in some degree; if anything by advising them of their rights. However, we cannot even do that for those we have not identified.

WFDB has achieved something important now that many governments pay attention to our needs and collaborate with us to provide some services. Many countries have enacted legislation to support individuals with deafblindness through various levels of support services. But we still need to do much more advocacy work to ensure that more services are available for many more individuals with deafblindness.

In many parts of the world, achieving more and better services for individuals with deafblindness is not as simple as enacting national

¹ www.internationaldisabilityalliance.org

legislation. Fighting for rights for services in many parts of the world has been a difficult challenge due to different beliefs, traditions, ignorance of disabilities as well as the lack of understanding of the unique nature of deafblindness.

We are still fighting at WFDB for many countries to accept and collaborate with us to strengthen our status and promote the development of a better quality of life for persons with deafblindness in many parts of the world.

In many countries, we have not formed enough alliances with other groups of persons with disabilities, including parents, professionals, etc. We need more people to know about us and that we are capable and useful to society. We just need to be identified, respected, given our freedom and space, without

being over protected. We need more cooperation.

We hope that soon will have the resources available for a worldwide program to hire guide interpreters and intervenors, to carry out training courses in leadership and advocacy to strengthen the current and future WFDB members.

We also need to consider the more marginalized individuals in our group, including elderly people, women, children and youth that need to develop their abilities.

I want to thank WFDB and in the name of all persons with deafblindness, for their continuous support and friendship. that the members of other disability associations, parents of persons with deafblindness and multiple disabilities and professionals that still offering invaluable services

for the group of persons with deafblindness.

I appreciate that DbI is supporting WFDB respecting our ideals, identity and actions. WFDB signed a Memorandum of Understanding with DbI as well as with WASLI², the World Association of Sign Language Interpreters. I Hope that this friendship, respect and collaboration will continue to strengthen.

For more information, contact Sonnia by email: sonniavillacres@hotmail.com



² Wasli.org

Possibilities: Recreation Experiences of Individuals who are Deafblind

Lauren J. Lieberman Ph.D. The College at Brockport, Justin A. Haegele-Old Dominion University, Maricar Marquez-Helen Keller National Center



Possibilities is an e-book that is comprised of stories of individuals who are deafblind published on-line through The American Printing House for the Blind (APH). The book starts out with an introduction about the importance of recreation especially for people who are deafblind. Then there are 16 role models who are deafblind and two Support

Service Providers who share their stories about their recreation experiences. The conclusion is a review of the common techniques the participants used to access successful recreation. The link to the book is www.aph.org/pe/stories.

The Table of Contents follows:

- Introduction
- Rachel Weeks-Triathlon
- Maricar Marquez-Running
- Kristine D'Arbelle-SSP-Swimming Triathlon
- Heidi Zimmer-Mountain Climbing
- Cody Colchado-Power Lifting
- Corrina Veasart-Ballet, Cheerleading, Rock Climbing, and Yoga
- Emily Desfor-SSP-Outdoor Adventures

- Kevin Frost-Speed Skating
- Ryan Ollis-Running
- Faye Frez-Albrecht-Soccer
- Quinn Burch-Dance, Horseback Riding and Running
- Nicholas Abrahamson-Hiking the Appalachian Trail
- Bruce Visser-Traveling
- Jason Corning-Running
- Sarah K.McMillen-Ice Hockey and Taekwondo
- Angela Theriault-Running
- Scott Keeler Bass-Biking
- Maria Marquez Dykman-Wind Chimes
- Conclusion

For more information or resources on this topic please see www.aph.org/pe or contact Dr. Lauren Lieberman llieberman@brockport.edu

Dr. Jan van Dijk (1937–2018)



We were so sorry to hear of the passing of world renowned Jan van Dijk in his home country of the Netherlands on January 23 of this year.

Dr. van Dijk has been an international leader in our field with more than 50 years of experience in deafblindness.

Jan worked first as an educator with children with combined vision and hearing loss at Sint-Michiëlsgestel Institute beginning in the late 1950's. In 1962 he started the first school for children with deafblindness, St. Rafael in Sint Michiëlsgestel, now known as Kentalis Rafael.

Jan was one of the world's leading experts in the education and development of children with deafblindness, tracing the development of his expertise back to the congenital rubella syndrome epidemics in Europe and North America during the early mid 1960's. Jan was the first professor in deaf pedagogues in the Netherlands (1990). Since that time Dr. van Dijk has been involved in the assessment of children with multiple disabilities, helping families and professionals to provide better services. His publications on children who are

deafblind have attracted world-wide attention. His work has received Perkins "Anne Sullivan Award" and Deafblind International's "Distinguished Service Award".

Dr. van Dijk's research has focused on many areas, including language and communication, attachment theory and stereotypical behaviour. He expanded his experience as a researcher to assess children with combined sensory impairments and multiple disabilities.

His approach to the education of children who are deafblind has led to the development of the concepts of resonance, attachment, co-active movement and natural communication. His research includes work with individuals with congenital rubella syndrome and those with CHARGE syndrome.

Dr. van Dijk had a wealth of experience assessing children by observing and following their movements, emotions and interest to gain insight into each child's learning process. His child-guided method of assessing was recognized and used throughout the world.

Dr. van Dijk was the author of numerous publications in the field of deafblindness and multiple disabilities and up until his passing continued to undertake assessments.

On an emotional level Jan was passionate about the children and families he supported, always approaching his work from the child's perspective and with sensitivity.

Our sincere condolences to Dr. van Dijk's family, he will always be in our hearts as will the legacy of his teachings and his work.



DbI Board Membership 2015–2019

Management Committee

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



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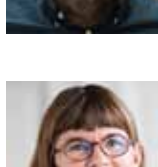
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Lifetime Achievement Awards

Evabritt Andreassen



Evabritt is an individual who has always been focused on developing high quality services for individuals who are deafblind. She has supported families and professionals and has helped them develop

their skills and knowledge. She is known as a seeker of knowledge both theoretical and practical.

Her professional career started with one deafblind student and developed into a position where she provided support to those working in a center for special education. In addition to supporting staff in her country she was involved in training teachers in several African countries.

A colleague who wrote a letter of support indicated that “long before networking was considered an ideal and efficient way of collaborating, Evabritt was involved in networking and was a competent facilitator and creator of networks in Norway”.

Her networking and collaboration with colleagues spread throughout the world through her participation in international deafblind conferences. She developed many contacts in the field and through her reaching out managed to keep herself updated on the current developments in the field. Her interest helped her maintain a high level of professional standard for both herself and her staff. In addition to attending conferences she was an organizer of an ADBN Conference in Bergen Norway in 2008.

Her colleagues respect her knowledge but they also appreciate her calm approach to situations and her good sense of humor. In difficult situations such as losing materials for a workshop at the airport, or having a guard with a machine gun outside her hotel room, she was still able to maintain her professionalism and with her personal strength everyone got through each challenge and able to fulfill their assignments.

The Lifetime Achievement Award is presented to Evabritt Anderaessen for an outstanding career in which she supported so many individuals who are deafblind – their families and her colleagues. She always offered her support and is someone who makes others look good through her caring, fun loving and supportive approach.

Evabritt continues to work as the leader in Unit for Dual Visual and Hearing loss and Deafblindness in western Norway.

Dorte Schultz Nielsen

Dorte Nielsen is an individual who has devoted her life to children and adults who are deafblind. She has worked with individuals with congenital deafblindness for 40 years. She has recently retired from Centre for Deafblindness and Hearing Loss in Aalborg, Denmark.

Throughout her career she has searched for new knowledge and perspectives to provide the very best programs for people who are deafblind. She is open minded and develops an understanding of life from a deafblind persons perspective.

Her strengths are many but her passion for communication is an area where she has focused. Her colleagues report that she is an expert in tactile communication. She sees potential in everyone she works with and wants them to have the best quality of life possible. A parent shared that “her ability to perceive the smallest signals and to be consistent in her reactions to them is the reason why my son opened up to the world and started to use and understand signs.”

Dorte is always willing to share her knowledge with others and she also seeks to learn new perspectives from colleagues. One of the supporters of this nominee said that she is always the first to interact with new staff members or students and is eager to work with them. Her approach to working with individuals has made a huge impact on the programs she works with.

She has done her work in a very humble way. Her colleagues describe her as shy but throughout the years she has inspired many colleagues around her to be curious and reflective and never to think that everyone knows it all.



This recipient of the Lifetime Achievement Award is known as an individual who is caring, engaged, honest and diligent. She is a role model to many who turn to her for advice and support.

Please congratulate Dorte Schultz Nielsen on receiving the Lifetime Achievement Award.

Secretariat News

DbI ManCom and the DbI Board met in Aalborg, prior to the DbI European Conference. Following these meetings, members participated in the Annual General Meeting which advised everyone where we were at as an organisation. Of special note during the meetings were discussions about DbI's Strategic Plan with its focus on Diversity and Technology. One aspect of the technology side was the introduction of the revised website. A significant aspect of its focus on Diversity was the announcement by the DbI President at the end of the conference that the next regional DbI conference would be held somewhere in Africa in 2021.



MEMBERSHIP

The membership during 2017 has increased due to the presence DbI had at the 9th Deafblind International European Conference in Aalborg, Denmark in September 2017. A remarkable and well organised conference that had many Networks and program sessions connecting people from around Europe and other parts of the world. A new network, called APA or Adapted Physical Activity Network was launched during the conference. The number of individual memberships has risen by 10 members since the last report, as we have also managed to re-instate some past memberships. DbI recognizes that the success it achieves worldwide greatly depends on the support of its individuals and corporate members to promote awareness and services. Becoming a member of DbI is as simple as going online through our website – www.deafblindinternational.org and completing the required application form.

CHANGES IN BOARD MEMBERSHIP

Since the last report there have been several changes to the Board due to changes of representative to the large corporate members.

These include:

- Kate MacRae replacing Kaye Collard (Able Australia)
- Lena Goransson replacing Michael Karlsson (Mo Gard-Sweden)
- Roland Flaig replacing Jutta Weiss (German Deafblind Consortium)

Worldwide memberships as of December 2017

Large Corporate	14
Small Corporate	45
Mini Corporate	3
Library	8
Individual	112

HOW TO KEEP CONNECTED

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



Via the Networks on the website:

www.deafblindinternational.org/networks.html

 www.facebook.com/dbiint

Gary Daly
DbI Secretariat
secretariat@deafblindinternational.org



Proudly Hosted by Able Australia

DbI Review – Sponsorship Guidelines

Corporate Member Organizations are invited to sponsor future editions of *DbI Review*. If interested, check out the Guidelines below.



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 sponsorships 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 advertisement
- 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 advertisement
- 2 articles (related to individuals who are deafblind)
- 15 x extra copies of *DbI Review*

Level 3 Sponsorship = 2000 Euro

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

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

For all levels of sponsorship, DbI reserves the right to not publish submissions that we deem for any 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.



STRATEGIC PRIORITIES JUNE 2015 - AUGUST 2019



Diversity

DbI will become a diverse organisation in all aspects including membership and Board representation.

1 PRIORITY ONE



Share Knowledge

DbI will support our networks to share knowledge and develop partnerships.

3 PRIORITY THREE



Social Media & Information Technology

DbI will invest in technology and social media to connect with our members and the global community.

2 PRIORITY TWO

Honorary Officers

President

Gillian Morbey
Sense UK
Email: Gillian.Morbey@sense.org.uk

Vice-President

Bernadette Kappen
The New York Institute for
Special Education
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Vice-President & Treasurer

Frank Kat
Royal Dutch Kentalis
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Immediate Past President

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Diversity Officer

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Networks

Acquired Deafblind

Network
Liz Duncan
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Adapted Physical Activity or APA Network

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CHARGE Network

Andrea Wanka
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The Lions McInnes House – Group Home for Deafblind Persons

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