



Con-nection Theatre School actors performing “Marriage” by Gogol

A message from the President

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

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

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Cover: Con-nection Theatre School actors performing "Marriage" by Gogol

Dear Friends and colleagues,

It was a real joy to meet everyone in August at the joint WBU and ICEVI conference in Florida. Combining our DbI meetings with our partners in larger conferences brings huge benefits. Funds for travel and time are precious nowadays so it's important to use these resources well.

It was fantastic to see a conference stream around deafblind and Multiple Disabled Visually Impaired (MDVI). I attended most of those workshops and was delighted to see new ideas emerging. As usual we all made important connections and re-established friendships. It was also good to reflect back a little on our 40 years and share some of those memories at our reception. As usual our Editor has captured some of the important moments and new thinking from the conference in this Review.

We are looking forward to the European DbI conference scheduled for 5th–8th Sept 2017 in Aalborg. Everybody is working really hard to make the conference a success with the planning of presentations, submissions of abstracts and all the practical organisation of venues well under way.

At the time of writing we are changing the DbI Secretariat. I must thank Debbie and the Senses Australia team for the brilliant contribution they have made. Matthew, Bronte and Elvira have developed and improved so many functions,



organised endless meetings, followed up every action and been a huge support to me and all the officers. Thank you. Senses Australia of course will not be a complete loss for us as they will still be a member of the Board.

We continue our important links to ICEVI and WFDB and remain in contact with both. Sadly, Sense International is losing their Director Carolyn Merry so the search is on to find a replacement. Congratulations to Andy Kerr in Scotland for being appointed as the new Chair of Quality Scotland and well done to our youth network for their Euro Disney trip. Thank you, Roxanna and Deafblind Ontario for recognising Shaun Gibbons from Sense with their fantastic award 'Friends of Deafblind Ontario Services'. You can read this and much more in this Review.

With Best Wishes
Gill Morbey
President

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Editorial

Welcome to the 58th Edition of DbI Review. Readers of DbI Review might wonder how articles are chosen for each edition of the magazine. The primary source of material is the result of a regular appeal to the membership and Networks requesting articles about best practises, research projects, technological changes, activities going on in their country, including conferences, that they wish to highlight. A secondary source includes presentations the editor may have heard during a conference.

Each time I assemble the array of articles submitted for each edition I continue to be amazed about the developments and the advancements in practises taking place in the deafblind field in so many countries. This edition is no different from past ones.

This edition begins with a special report about deafblindness in Japan from international consultant Jacques Souriau. Jacques is a retired professional from the deafblind field, well known in the DbI community as a past president of DbI, and currently a member of the DbI Communication Network. Jacques was invited to Japan earlier this year to work with some of their professionals and lecture about the current studies and methodologies in deafblind communication. His article begins with a thought provoking statement: "In the extraordinary world



of deafblindness, one can feel at home in any place on this planet; while cultures may differ, when it comes to deafblindness, the challenges are the same". Jacques reports on his observations of various educational programs involving children and adults with sensory impairment. Educators and family members welcomed Jacques's lectures and coaching, his wide-ranging advice about the importance of individualized student development programs, video analysis, close parental involvement and his demonstration of special physiotherapy techniques to improve the quality of communication and consciousness of an individual's emerging bodily actions. It is indeed a fascinating article.

I had the opportunity to attend several relevant deafblindness presentations during the ICEVI Day Schedule, during the WBU-ICEVI Joint Assemblies in Orlando, August 22, 2016. Three of those appear in this edition as feature articles: 'Responsible Inclusion', 'Peace of Mind: Mindfulness techniques for (continued on page 90)

Contents

A message from the President *Page 2*

Editorial and contents *Page 3*

Vice President's messages *Page 4*

General Articles

Aspects of Deafblindness in Japan *Pages 5–10*

Responsible Inclusion *Pages 11–16*

Peace of Mind: Mindfulness

Techniques for and stress control in the MDVI Curriculum *Pages 17–20*

The importance of the bodily-tactile modality for students with congenital deafblindness who use *Pages 28–34*

Augmentative and Alternative Communication Gestures in Augmentative and Alternative Communication *Pages 35–39*

Participatory Curriculum Development to meet Community Needs *Pages 69–73*

Developing a new Nordic Definition *Pages 76–77*

Profile of Lea Hyvarinen *Pages 78–79*

Network News *Pages 21–27*

CHARGE, Outdoor, Usher, Research, Communication, Youth

Conferences *Pages 40–48*

European Deafblind Conference

CHARGE Pre-Conference

Usher Pre-Conference

Youth Network Activity

DbI Conference 2019

Groningen Conference Overview

Country News *Pages 49–68*

Africa, Australia, Brazil, Canada, France, Germany, Ireland, Malawi, Russia, South Africa

Research *Pages 74–75*

Quantitative Data Analysis

Book Announcement *Pages 80*

Deafblind International Membership and News

Board membership 2015–2019 *Pages 81–83*

Secretariat news *Pages 84–85*

DbI Strategic Plan *Pages 86–87*

DbI Awards *Pages 88–89*

DbI sponsorship guidelines *Page 91*

Officers and Corporate membership listings *Page 82*

Vice Presidents' Messages

BERNADETTE M. KAPPEN REPORTS:

Deafblind International is all about making connections. This was especially true when the DbI Board held its Annual Meeting in Orlando this past August. The Board worked as a group to further develop the strategic plan and discuss issues that will improve awareness of the needs of individuals who are deafblind. We were so fortunate to have Geir Jensen, President of the World Federation of the Deafblind and Colin Low and Mani from ICEVI participating in discussions at our meeting. Strengthening our relationship with both organizations will increase the capacity to support the needs of children, youth and adults who are deafblind. In addition to the formal meeting, DbI hosted a reception which provided an opportunity to reflect on the 40 Years that DbI has been working



around the world. So much has been accomplished and every member of DbI can be proud of the work they do.

I recently attended a luncheon hosted by Ambassador Oh Joon to discuss issues related to the Convention on the Rights of Persons with Disabilities (CRPD). This was an opportunity to share with the group the needs of individuals who are deafblind. Ambassador Oh Joon is the current President of the CRPD Committee. He will be leaving this post and arranged the luncheon to review what has happened during his term and begin a transition as the Ambassador of Bulgaria steps into this role.

As we look to 2017, there are many exciting activities happening around

the world. The members of DbI will have an opportunity to get together to learn from each other, to network and to have fun at the upcoming European DbI Conference in Aalborg. The scientific committee and the host committee have been working very hard to make this a memorable event. I want to encourage you to send in nominations for the DbI awards. This is always a special time during a conference. The information for submitting nominations is on the DbI website (www.deafblindinternational.org). The deadline for submitting nominations is May 12, 2017.

Please continue celebrating our 40th Anniversary and your successes as you provide outstanding services on a daily basis.

Bernadette M. Kappen
bkappen@nyise.org

FRANK KAT REPORTS:

Dear Friends and Colleagues,

I was planning to share with you how hard we worked together at the DbI board meeting during the Orlando conference this summer. I was going to say that a clear line of approach to social media was discussed and agreed upon, as was the need for diversity in our organization. In short, hard work was done for the future of Deafblind International.

Recently I received a message from a client of Kentalis that was surprising to me. The message began with 'Hello director'. This client emails me quite regularly, usually when he believes something could be improved or should be done differently. On this occasion, he disagreed that a beer bottle should be allowed in 'his' kitchen. This was not acceptable, he continued, and



in my capacity as director, I should take action to prevent this kind of practice. Now, I value this kind of contact a great deal, whether it is verbal or via email. It is an art to listen and observe well, and to discuss matters and act accordingly. It is not important whether it concerns a beer bottle, the weather, the day programme or anything else. It is the contact that is valuable and the essential points communication with this man. As a manager, it is so easy for me to lose sight of this. That is why I attach such great value to it. After all, the quality of decisions depends on the substantive need. I was, for instance, part of a fabulous activity in Paris with the DbI Youth Network, bringing children and

young people from different countries together to meet each other and to have an adventure.

This activity was not simply about having fun; it also focused on communication and meeting each other. How these youngsters simply reached out to one another and spent time as a group, took responsibility when necessary and looked after each other, really was a sight to see. The time furnished me with amazing experiences and a number of great stories.

I ask you to share these kinds of experiences and stories so that we may inspire and help each other to do the best we can. This would be also an awesome step towards a more interactive website or Facebook page. We look forward to this. Let's stay in touch!

Frank Kat (F.Kat@kentalis.nl)

P.S. Oh yes, please remember to register for the 2017 DbI European Conference (early bird) and keep your diary clear for the 2019 World Conference.

Aspects of deafblindness in Japan

Jacques Souriau

Introduction

In the extraordinary world of deafblindness, one can feel at home in any place on this planet. Cultures differ, but when it comes to deafblindness, the challenges are the same.

In June 2016, I was offered the opportunity to experience the universality of deafblindness in a country where the culture is quite unique: Japan. It is a fact that international collaboration and professional publications are greatly influenced by European and American (private or public) organizations using English as the main language of communication. As a result, too little is known of countries (and there are many) which do not participate as intensively in this network. Therefore, when I got an invitation to take part in a project that would give me the possibility to have a direct contact with deafblind people, family members and professionals in Japan – a country known to me for its sophisticated culture and advanced technology, I said “yes” without hesitation.

This invitation came to me from two colleagues: Mrs Megue Nakazawa and Professor Masayuki Sato. Mrs. Megue Nakazawa, once a senior researcher at the National Institute of Special Education in Japan¹, she

now occupies the position of Principal at the Yokohama Christian School for the Visually Impaired (Kunmoo-Gakuin)². Her professional activities led her to develop a strong interest in blindness and deafblindness. I had the pleasure to meet her on the occasion of a long study visit in Norway and France during the 1990's as well as during various DbI conferences. At the Yokohama Christian School for the Visually Impaired (where there are also six deaf individuals, she is one of the successors of Mrs. Sadako Imamura, once a familiar figure at past DbI conferences. As the principal of a school for multi-disabled blind students, Megue Nakazawa is interested in improving the competencies of her staff members as communication partners for the deafblind children, especially with regards to sustaining the children's engagement maintaining contacts and also exploring further the dynamics of tactile communication. Her hope is also that these newly developed communicative competencies would be equally useful and relevant for the other students of the school who are not deafblind.

Professor Masayuki Sato is in charge of the Research and Support Centre on Higher Education for the Hearing and Visually Impaired at the



famous Tsukuba University of Technology³. In this context, he has contact with a few students with acquired deafblindness and leads a project aiming at making available an E-learning system that would work for them. This research is supported by a Scientific Research Grant from the Japan Society for the Promotion of Science⁴.

Thanks to this grant, I was able to collaborate with Megue and Masayuki to meet people with congenital and acquired deafblindness and organize working sessions with various professionals and researchers.

Consulting and Being Practitioners Again

The first part of the project was focused towards the congenital deafblind children among the 30 multi-disabled blind children who are enrolled in the Yokohama Christian School for the Visually Impaired (KUNMOO-GAKUIN). The plan was for me to first

¹ <http://www.nise.go.jp>

² Kunmoo-gakuin 181 Takenomaru Naka-ku, Yokohama-shi Kanagawa, 232 JAPAN

³ www.tsukuba-tech.ac.jp/english

⁴ <https://www.jsps.go.jp/english>



Megue Nakazawa and Professor Masayuki Sato

observe the activities of those deafblind children then lecture to the staff at the end of the day. However, if one wants to understand the communication profile and developmental potential of each individual child, simple observation is not enough. It is difficult to provide relevant advice without the kind of information obtained from direct contact. Therefore, I made a personal encounter with each of the children, with each communication interaction filmed to provide the staff members and families with material for video analysis. Through these sustained personal interactions, I could feel and explore directly each child's favorite contact modality, allowing them to expand their own initiatives. As well I was able to identify their present competencies and potential for further improvement.

In other situations, my lack of mastering Japanese sign language considerably limited the richness of our exchanges. To resolve this, we organized

small online coaching sessions where I was giving guidelines to a professional while he was interacting with a child. This method requiring mutual trust and active collaboration proved to be quite successful. For example, together with a teacher (following a request from the parents), we managed to help a child to use tactile (instead of visual) signing for communicating while using her residual vision to access events around her. This resulted in her changing her physical approach for accessing information and communication. With another child, the teacher had set-up a challenge for her to understand and differentiate the signs (and the concepts) for 'bread' and 'rice' in the context of an activity where she could touch and eat these two kinds of food. The success of such a project depends a lot on the competency of the teacher not to interrupt the tactile contact and to react to the child's initiatives in a structured and playful way. During that session, the child did not initially produce

these two signs; but later in the day, she was seen producing them for herself, in a thinking moment, proving that something had built up in her mind during the exchange with her teacher, equipping her with a new tool for thinking and, hopefully, for communicating.

Another anecdote worth reporting was meeting a 19-year old male student at the school who was quadriplegic. My wife, Mimi, who accompanied me on the trip to Japan (and who worked through her professional life with congenital deafblind children), was observing my interaction with this young man. She believed that she could work with him using the bodily approach based on the Feldenkrais method^{5,6}.

This method is a form of physiotherapy based upon observing the bodily initiatives of the individual and reacting to their responses through focusing on communication and at the same time enhancing the quality and consciousness of the individual's emerging bodily actions. He clearly engaged in this relationship with pleasure, concentrating for such a long time, that the tiredness of my wife and our time schedule made it necessary to put an end to the session. Staff members (including the financial manager of the school) observed this interaction and expressed interest in exploring this approach further. This procedure appeared to be in line with their own practice and offered

⁵ Feldenkrais M. (1985) "The potent self" traduction française (1990) "La puissance du moi." Editions Robert Laffont, S.A. (p.21).

⁶ Learning and Communicating through Movement: DbI Review 57, July 2016

further possibilities for the young man's development. The following day, the staff member in charge of him tried the same method through my wife's coaching. Its relevance to this young man became evident, but of course its success will depend on proper training and practice.

During the three days spent in the Yokohama Christian School for the Visually Impaired, it seems that some changes happened thanks to the mutual engagements between the staff members, the students and us, the visitors. A climate of trust developed, based on very practical shared experiences that were commented upon during the evening lectures. The staff members discovered the importance of video analysis for understanding the dynamics of interactions and co-constructing a frame of references allowing a better adjustment to each individual developmental profile. At the same time, some mothers spent time in the school to observe our activities with their children. It was an occasion for them to have access to our

methods of observation and to make links with their lives at home. Hence, the sessions with the children took actually the form of a 'quadrilogue' involving the child, the mother, the teachers and the visitors. And a fifth element must be added to the picture: these exchanges would not have been possible without the permanent availability of Megue Nakazawa, the principal, who took care of the Japanese-English translation.

This dynamic learning atmosphere around the children had also important witnesses: a team from the TBS TV Network, led by Mr. Toshiyuki Kawakita, was filming us all the time with a purpose worth mentioning. Mr. Kawakita is following how some important social problems are being dealt with through state, private or even individual initiatives. Deafblindness happens to be one of the issues that he has followed up since a decade ago. Mr. Kawakita is perfectly acquainted with the questions related to congenital deafblindness and knows very well about the Yokohama Christian School for the Visually Impaired.

A visit to Tsukuba University of Technology

After three busy days in the context of congenital deafblindness, we travelled to the Research and Support Centre on Higher Education for the Hearing and Visually Impaired in the Tsukuba University of Technology (about one hour from the center of Tokyo) where Pr. Masayuki Sato took over the lead of the second part of my program.

Tsukuba University of Technology offers special university programs (including full boarding) for students with sensory impairment. I had the opportunity to visit several University programs including a design course for deaf students, an acupuncture training program for blind students and met a team in charge of sport activities for the blind. During these visits, I was quite impressed by the level of accessibility equipment available for mobility and accessing information. It was pleasing to observe that Japan provides supports for students with sensory impairments.

However, this level of accessibility is not sufficient for deafblind students. Pr. Sato wishes to enroll a brilliant young deafblind man into the graduate program of Tsukuba University. He managed to get a grant from the Japan Society for the Promotion of Science to design an E-learning system providing the deafblind student with a distant access to lectures and discussions through an automatic braille captioning system. There are definitely many challenges to make this initiative work for this



Mimi's results using the Feldenkrais method with Huru

young man to allow him to participate in and understand the lectures, which are much more than just text! But the professor is confident that the collaboration between the university team and the deafblind student will produce solutions for designing the project in an advanced and feasible way.

Two fascinating interviews in Tokyo

After a couple of days at the Tsukuba University of Technology, we went back to Tokyo where two important interviews had been arranged for me with two people who are deafblind people: Miyuki Ara and Atsushi Mori.

Miyuki is a young lady who has acquired deafblindness. To communicate, she uses Finger Braille⁷, a method that was created in Japan in 1981. With Finger Braille, the interpreter sits next to the deafblind person and taps characters in braille, onto the uppermost digit of the middle three fingers of each hand like the keys of a braille writer. It follows the traditional system in Japanese braille of hiragana and katakana characters⁸. This method requires a good knowledge of braille; it is quite fast and it is also possible to symbolize emotional aspects. With two interpreters, one for English-Japanese translation and the other for finger braille, we managed to have a long and fluent conversation. It took place at the Meiji Gakuin University⁹ where she is studying. Most of our



Miyuki Ara and interpreter

conversation was focused on the education of congenitally deafblind children, a situation that was obviously intriguing to her. We addressed typical but central questions like how these children understand the world; how they build up concepts and how language can be introduced. Miyuki recently published a book based on her own experiences; but our conversation proved that she is also interested in accessing other types of deafblind experiences.

Atsushi Mori is a fascinating young man. He was born totally deafblind but the aetiology is unknown. I had the occasion to meet Atsushi before during the DbI World Conference in Perth (2007). He was much younger but was already fluent in sign language along with good reading skills. I remembered that we managed to have a conversation using tactile signing in spite of the differences between French and Japanese sign languages, but, of course, an

interpreter was necessary for a more precise and extensive exchange.

This time, I met Atsushi in the Japan Lutheran College in Tokyo¹⁰, along with Pr. Sato and Megue Nakazawa. Atsushi is now 24 years old and he uses sign language (not finger braille) for conversations. I did not know what to expect from this new encounter, but I quickly realized that Atsushi was perfectly prepared. He told me that he was working on a thesis that would allow him to join the Tsukuba University of Technology where Pr. Sato is working to make the program accessible to him. He wanted to know my opinion about the feasibility and relevance of the topic he had chosen: *The difficulty understanding 'Fantasy' for a congenital deafblind person and the process by which he came to recognize, understand and appreciate Fantasy?* The reason for him to choose such a problem is extremely interesting. His first idea had been to write a

⁷ fingerbraille.com; <https://www.youtube.com/>

⁸ <https://coscom.co.jp/hiragana-katakana/index.html?watch?v=eTC-ZmILCu4>

⁹ www.meijigakuin.ac.jp/en

¹⁰ www.luther.ac.jp/english



Atsushi Mori and interpreter

thesis on his own experience with deafblindness, which is a wide and quite common topic among deafblind people who managed to write about their own disability. But an event made a new and more precise idea spring in his mind. One morning, he told his mother that he had just met the girl next door. His mother was quite surprised because she knew that the girl next door was not at home. She said that this event must have happened while he was dreaming. This statement was a shock for Atsuchi, because it made him aware that he had treated something imaginary that happened only in a dream as if it were real. He realized that he did not know really what fantasy is. This event was the last part of his progressive elucidation of the differences between reality, fiction and fantasy.

Atsushi was able to read textbooks and stories in his later elementary school years and he could understand fiction, because fiction is based on reality and logical

cause-effects connections; but he had trouble with a world of fantasy where a fish can speak or fly. And then he realized that the world of his own dreams (and other people's dreams) was full of unrealistic and illogical events. This discovery puzzled him and triggered his interest in sharing this experience with other people and making it the topic of an academic research. One could venture in trying a hypothetical explanation for this difficulty differentiating reality from fantasy in the following manner: Sighted-hearing people are reminded all the time that there is something real around them because they have to negotiate with it when they move and communicate. But when you are deafblind, you spend a big part of your life with your own thoughts or within a perimeter of accessibility which is limited to the tactile channel and reduced by the lack of easy mobility; therefore, the world inside and the world outside can

be easily mixed up. This is a possible explanation but it has to be explored further.

I told Atsuchi that his thesis could be an exceptional contribution to the knowledge of how congenitally deafblind people think and construe reality. There are very few people on the planet that were born totally deafblind and that are, at the same time, able to fully understand and express themselves in the language of the culture they live in. They are the only ones that live in the country of the 'congenitally deafblind' and can report directly to the citizens of the country of 'sighted-hearing' people about what happens where they live.

This happens also in the world of autism where people with Asperger Syndrome¹¹ have both the personal and permanent experience of autism and can, at the same time, inform other people about the way they understand the world, the challenges they meet and the solutions they build up. In this way, they help to understand better what is the life experience of other people with autism who do not have the possibility to express and promote the form of their relations to life. Atsuchi could therefore be a precious messenger from the 'world of congenital deafblindness' and inform us about things that other congenital deafblind people cannot express directly and clearly, leaving families and professionals with the

¹¹ www.webmd.com › Brain & Nervous System › Autism

Aspects of deafblindness in Japan

tough task to find ways to access it (for instance through video-analysis based on relevant and sophisticated semiotic frameworks). Atsuchi shared also with us another interesting problem that sheds light on how language competencies and knowledge of the world connect in the life of congenitally deafblind people. Atsuchi is perfectly fluent in sign language and reads braille, but he suffers from the gap he experiences between his full-fledged linguistic competencies and his limited accumulated knowledge of the world he lives in. This is probably the reason why he became an expert in the public transportation system of Tokyo. His precise daily and direct experience with it gives him a sound ground for building up a secure overview of the whole system. In many other domains of life, his language works on quicksand for lack of direct bodily experience. This is a typical problem in the context of congenital deafblindness where teachers and family members must make a point to secure enough practical bodily experience for language to develop on a sound basis. In the case of Atsuchi, what is exceptional is that he developed language (as a system) much faster than the life experience it should be connected to. In many ways, Atsuchi is what ethnologists call an informant¹², a native who can bring direct and relevant information about the culture which is studied. Having the privilege to have a long

conversation with him was a wonderful conclusion for this fascinating trip in the world of deafblindness in Japan.

Concluding the visit

These eleven days were very busy, but some free days gave us the opportunity to get more than a decent share of the Japanese culture under the careful guidance of Megue Nakazawa and Masayuki Sato, including a wonderful tea ceremony, public baths, wonderful sushi's, temples etc. Everywhere we enjoyed

a very warm and active experience of collaboration with the professionals and the families, and hopefully learned a lot from each other.

Jacques Souriau (jacques.souriau@gmail.com) is a former director of **CRESAM** (the National Resource Centre for Deafblindness in France) and a past President of **DbI**. Jacques lives near Poitiers France and continues to be active as a consultant and lecturer in the field of deafblindness.



Jacques communicating with Miki



Jacques communicating with Sora

¹² www.anthrobase.com/Dic/eng/def/informant.htm

“Responsible Inclusion”

Considerations in Providing Access to Quality Education for Children who are Visually Impaired with Additional Disabilities¹

Dennis Lolli and Deborah Gleason

The Global Challenge

There are an estimated 46 million children and young adults (ages birth–24) around the world who are visually impaired, but fewer than one in 10 children with visual impairment in developing countries goes to school. The majority of this population lives in poor countries, where a lack of resources and cultural stigma of disability prevents individuals with visual impairment from accessing the appropriate education they need to reach their full potential. Approximately half of these children are visually impaired and have additional disabilities.

Children and youth with multiple disabilities and deafblindness are among the world’s most vulnerable – and the least likely to receive an education. Instead they are often left at home, cut off entirely from the education system. Others are placed in the care of orphanages and children’s homes, where they may have access to care providers but little to no interaction with well-trained educators. Inadequate teacher training is also a fundamental problem. Without specialized trainings, teachers of children with visual impairment and additional disabilities often struggle to meet the unique needs of their students.

Achieving Education for All

In support of *Education for All* goals, Perkins International² is committed to advocating for the advancement of the education, economic and political rights of all children and adults who are blind and visually impaired. Since 1989, Perkins International has worked with local partners in more than 60 countries around the world to expand educational opportunities for children who are visually impaired with additional disabilities.

As a result of over 25 years of international work, we have identified several common policy and regulatory barriers towards ensuring children receive quality education services. To eliminate these barriers, we recommend that educational systems include, but not be limited to, the following elements:

1. A functional definition and a formalized system for identifying children with visual impairment and multiple disabilities
2. Training for special and regular education teachers on methods of teaching children who are visually impaired with multiple disabilities
3. Funding structures based on the needs of children with multiple disabilities who often need a smaller teacher to student ratio
4. Knowledge of curriculum accessibility
5. Systems for assessment and evaluation of students
6. Support, encouragement and training for families to be included in education planning and development
7. Vital linkages with other government agencies and the private sector to develop comprehensive systems of transition, support and continuity.



Dennis Lolli



Debora Gleason



¹ Paper presented at Concurrent Session 7 (Education for children with visual impairment and additional multiple disabilities or deafblindness), ICEVI Day Program (August 22, 2016), WBU-ICEVI Joint Assemblies, Orlando Florida

² Perkins International (www.perkins.org) / Perkins School for the Blind is a large corporate member of DbI.



Policy Recommendations

Disability advocacy efforts were greatly enhanced in 2006 when the United Nations adopted the Convention on the Rights of Persons with Disabilities, and were furthered when the Convention entered into force on 3 May 2008, with ratification by the 20th country. The Convention mandates accessible education without exception for all children with disabilities, including providing the necessary

supports when needed. In addition, the Convention specifically draws attention to the needs of students who are deafblind and/or have severe disabilities. As of February 2016, 160 countries have ratified the Convention, agreeing to be legally bound by the Convention and to adapt their domestic legislation to the international standards of the Treaty.³

Perkins International is committed to contributing to the Convention's implementation by expanding

access to education around the world for children who are visually impaired with additional disabilities, including deafblindness. This unique population of learners, though diverse, requires specific education planning as a result of reduced access to environmental information as a consequence of reduced capacity of distance learning channels of vision and hearing. To provide opportunities for children to achieve quality of life, planned lifelong education intervention is needed.

It is our recommendation that the following issues be considered in the development of comprehensive programs addressing education for all for children who are visually impaired with additional disabilities:

- Develop a functional definition for this population and systems for screening and identifying children with visual impairments
- Offer a continuum of services from early intervention through transition to adult life
- Establish a variety of school placement options, including special schools, classrooms, resource centers, and regular education classrooms
- Assure that each child has an individualized education plan
- Train general and special education teachers in best practices and methods for educating students who are visually impaired with additional disabilities
- Include families as full educational team partners and provide ongoing training and support
- Assure expanded time for education and training

³ "Rights and Dignity of Persons with Disabilities." UN News Center. UN, n.d. Web. 16 Feb. 2016.

Systems of Evaluation and Identification:

Without the development of a targeted definition along with systems of identification, children are often mislabeled. This leads to children being excluded from programs or placed in programs with inadequate training and planning. This is particularly true if clinical and functional screening is performed by persons without basic training in the field of sensory abilities.

Continuum of Services:

From early intervention through transition to adult life planning, linkages need to be established between services in partnership with families and agencies. Systems need to be evaluated to assure that specific education needs and personnel development are addressed through planning and training. Consequently, programs with trained personnel in specific methods of education are essential to support life-long learning and development.

Range of Placement Options:

Experience around the world has shown that the education needs of children are diverse and that individual children respond differently to a range of environments. The population of children who are visually impaired with additional disabilities and/or deafblind is low-incidence, yet through the education process a variety of teaching approaches are needed. Specifically, in education beginnings and linkages to adult life, these children often require specialized

instruction in structured environments to open the door to wider possibilities of learning and maximized education outcomes. Often specific centers are required both as a resource to inclusive education and as learning environments responsive to individualized needs. Also, children will need access to instruction in a range of community environments in order to apply learning to societal integration and expanded opportunities.

Individualized Education:

Inclusive education must bring together the best of education and special education in service to the individual child and his/her family. Though part of a larger population of children who respond to common methods of education, each child who is visually impaired with additional disabilities and/or deafblind is a unique learner whose specific capacities and abilities need to be identified and nurtured. This necessitates that a comprehensive plan of education be developed in conjunction with families and a trained education team. This plan should address specific curriculum adaptations which provide individualized access to education. Classrooms should provide access to one-to-one instruction tailored to the child's sensory disabilities. Children who are visually impaired with additional disabilities lack opportunities for incidental learning; anything beyond their fingertips may be unavailable to them.



Systems of Personnel Development and Training:

To truly be accessible, education systems need to develop a comprehensive plan for the development of teachers and education team members with competencies to address the unique education needs of children who are visually impaired with additional disabilities. These systems should address both pre-service and in-service development and be available to special and general education professionals who are part of the child's education team. Key topics with which teachers and education team members should be familiar include, but are not limited to, communication, literacy, individualized educational planning, functional curriculum, instructional strategies, sensory development, and orientation and mobility.



Parent Training:

For many children with multiple disabilities, parents are the life-long voice representing their needs and rights to education. Parents and family members are powerful advocates for ensuring that their children are included in systems of education. Thus, on-going parent training and support is essential to ensure quality services throughout the education process.

Expanded Time for Education:

In many systems, children who are visually impaired with additional disabilities are receiving part-time education due to limited resources and trained personnel. In reality, the rate of learning impacted by reduced sensory capacity is slower and requires more time on a daily, weekly and yearly basis. Education needs to not only address standard curriculum but also reduced access to incidental and environmental learning.

ABOUT PERKINS INTERNATIONAL

All children with visual impairment can learn – and thrive

Perkins International's global mission is to ensure that all underserved children and young adults with visual impairment receive a high-quality education. We work to break the isolation and neglect these children face, transforming their futures through the power of learning. We believe that all children can learn – and thrive. Education enriches the lives of individual with visual impairment and prepares them for an active role in their families, school and communities.

Four strategies help us transform blindness education around the world

Perkins International uses a proven model for the sustainable improvement and expansion of educational programs for children with visual impairment and multiple disabilities, including deafblindness. Developed by our expert staff of special educators, our model is the product of decades of experience working inside classrooms, orphanages and small villages in some of the poorest countries in the world.

1. Building local partnerships

We work with hundreds of local partners: schools, orphanages, daycare facilities, teacher-training programs, government agencies, family advocacy groups and more. Powered by our expert training and strategic support, these partners help us transform the educational landscape in their regions.

Our partnerships span the globe. Whether it's helping a small daycare and rehabilitation facility in Croatia grow into a regional resource in the Balkans, or working in India to develop new early intervention services for infants and toddlers at one of Asia's first-ever deafblind programs, we are dedicated to building long-term partnerships with local organizations. The end result is sustainable improvements to blindness education around the world. And it's all fueled by our robust partner network.

2. Teaching the Teachers

It takes a complex set of skills to teach children with visual impairment. In many regions of the world, teachers often lack the training required to do the job. That's why Perkins



International is committed to increasing the supply of qualified teachers of children with visual impairment and multiple disabilities.

We hold hundreds of trainings each year around the world. They range in scope from workshops for educators of all experience levels to graduate-level training courses at local universities. Perkins International also prepares the next generation of leaders in the field with our flagship training initiative, the Educational Leadership Program (ELP). The ELP offers select professionals nine months of advanced training on the campus of Perkins School for the Blind.

3. Empowering Families

It's vital that the families of children with visual impairment have the support they need and a voice that can be heard. Perkins International equips parents, siblings and other family members with the resources necessary to become effective caregivers and advocates. This helps ensure that the children we serve also have a reliable support network outside the classroom.

We also promote the formation and growth of family support organizations. Such groups include a full-service agency in Kenya working to empower the families of children with visual impairment in one of the world's largest slums, and a support group in the Philippines started by a handful of parents that now includes hundreds of members and influences national education policy. What unites them all is the unrivaled passion and urgency families bring to the cause.

4. Advocating for Change

Advocacy helps Perkins International build a foundation of understanding, acceptance and support for individuals with disabilities. From community outreach efforts with our partners, to working with government officials to enact laws that promote access, inclusion and high-quality education programs, we're doing our part to build a better world for people with visual impairment.

Government support is key to accelerating this process. That's why Perkins International has a long history of partnering with regional and national ministries of education across the globe. Successful advocacy can be challenging in cultures where disability remains stigmatized. In this sense, we are working alongside our local partners to fundamentally change the way these societies view people with disabilities.



How Perkins International Can Help

Perkins International can contribute to the development of policies and services to benefit children who are blind or visually impaired with multiple disabilities. Specifically, Perkins can:

- Train teachers, parents, and school administrators on best practices in the education of children who are visually impaired with multiple disabilities
- Strengthen the capacity of schools and agencies to develop or expand quality educational programs
- Adapt national curriculum to meet the needs of children with visual impairment and multiple disabilities
- Empower parents to become effective advocates for their children's education
- Support policymakers to incorporate the needs of children who are blind or visually impaired with multiple disabilities into policies and services
- Support the development of university training programs for teachers of this population of students
- Make available, in a variety of languages, selected educational resources and literature for teachers, students, parents and the general public
- Help governments to implement policies and practices outlined in the United Nations Convention on the Rights of Persons with Disabilities and Optional Protocol

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“Perkins International can contribute to the development of policies and services to benefit children who are blind or visually impaired with multiple disabilities.”

Peace of Mind: Mindfulness techniques for and stress control in the MDVI Curriculum¹

Aine Murphy

There is a growing awareness that 'Mindfulness²' tools and techniques can have a vital role to play in trauma, attachment issues, illness, anxiety and any number of mental health issues. This is especially relevant when working with young people with Multi-Disabled Visually Impairment, young people who have no physical voice, young people with a physical disability as well as emotional and cognitive disabilities. This work is also successful in working with young people who are DeafBlind. Over the last three years, I have been privileged to witness the very real and significant impact a sustained mindfulness program has had on the lives of these young people.

In the Royal Blind School, Edinburgh³, we run a program of Mindfulness. Working closely with education staff and psychologists we have tailored an individualised program specific to the needs of each pupil. This is underpinned by recent developments in neuroscience, more understanding of brain development, psychology and of course, education.

We are fortunate to work closely with psychologist Stan

Godek who wrote the book: Mindfulness Techniques for Children and Young People⁴. This publication is a practical guide, which includes the work we have done together as a series of case studies and examples. This partnership with Stan has taken the work from the realm of 'new age' and 'airy fairy' into a science based activity, supported by statistical evidence and recorded results.

Mindfulness is essentially the ability to rest the mind in the present moment, focusing on a specific object or a task, exercise or movement. It creates a sense of relaxation, space and peace – and at the same time generates a sense of alertness which can help to lessen arousal or distraction. Mindfulness activities will take the child out of what we call the 'red zone' helping them to cope and have more control over stressful transitions through the day. Transitions that you or I may not find stressful but I'm sure you know the children who can't cope with the daily routine, especially if that is disrupted by any unforeseen circumstance. We were on a difficult journey with some pupils. One comes to mind – a boy who is blind and autistic



and experienced many 'melt downs' throughout each day. Mindfulness is not about teaching children to meditate or to practice yoga or Tai Chi. While mindfulness involves the therapeutic use of those techniques, it is also about relaxation and enjoyment, imaginative thinking and having fun.

What was our starting point? First, we recognised that our pupils are always being challenged to be the best that they can be. To achieve and meet targets. We have very high expectations for our young people and they almost always rise to each challenge. Whether that challenge is using a head operated switch to get to the next page of the story, or learning braille math for a national exam – that's where the focus and drive is. We will go out of our way so that

¹ Paper presented at Concurrent Session 7 (Education for children with visual impairment and additional multiple disabilities or deafblindness), ICEVI Day Program (August 22, 2016), WBU-ICEVI Joint Assemblies, Orlando Florida

² <https://www.psychologytoday.com/basics/mindfulness>

³ <https://www.royalblind.org/education>

⁴ www.childrenscotland.org.uk/.../mindfulness-techniques-with-children-and-young-...

each pupil achieves the best that they possibly can. But where is the space? Where is the quiet? Where is the peace and stillness for the mind and body just to be? That is the space where we now know that healing, acceptance and learning to regulate our own emotions can take place. That space is where deep relaxation can start to change the body and rewire the brain. That was the impetus to start a mindfulness program.

Breathing is hugely important. Nobody teaches us to breathe. We are alive so we all assume we are doing ok. It wasn't until we called in some experts (there is a 'correct breathing trust'!) and did some of our own learning to discover that breathing is a big issue. Many of our pupils sit in strange positions, hunched over in wheelchairs, leaning forward, demonstrating a lot of involuntary movements resulting in their breathing being light and shallow. We have a boy who breathes in through his mouth and out through his nose. Very few of our pupils could breathe down into their tummy, long and slow, consciously.

We begin each session with some body awareness scripts to focus attention on breath and body. Many pupils have an abstract knowledge of their body so this helps them to learn about their breathing on whatever level they can understand. "In through the nose and out through the mouth. Relax your tummy, relax your back" might be all the words you use. Or it may be a more in depth scan of the body helping pupils unwind in preparation for the session. Thinking back



to those early days, it is a complete contrast to what we encounter now. The pupils did learn to breathe and relax and it is a totally different atmosphere than in the past.

So, breathing and body awareness is a good starting point. We then went on to create visualisation stories that were relevant for each pupil and were to become their own 'happy place'. How do we develop a visualisation program that has such emphasis on imagination? With the lack of sight and experience, many pupils need something physical like a signifier to make a link or a connection to the environment and world. We can't just dive off into a nice relaxing scene that involves, for example, a walk in a green forest with tall trees swaying in the wind and a babbling stream nearby, or sitting in the sun on a sandy beach by the ocean listening to the lap of the waves. To many of our pupils, these are just words with no tangible link to experience. Many of them have no experience of the forest or can't imagine being calm by the ocean.

We wanted to create a visualisation story that was meaningful to our pupils such that they could use for relaxation to become their 'happy place'. This in turn could be used for regulating their emotion.

We started with what we called 'Sensory Stations'. The Sensory Stations comprised of five sensory areas and each pupil could take their time exploring each area. Exploring it in a 'meditative' way with minimal discussion, with gentle background music allowing them to focus on

the feeling and smell of each thing. The stations were as follows:

- Chiffon scarves infused with peppermint oil or a preferred scent like mums' perfume. The pile should be large enough to explore and hide.
- A small tent that can be put up indoors. It should contain a sleeping bag or duvet to crawl into, lie in or cuddle up.
- A pile of fur – to experience the feel and texture but also big enough to crawl under.
- A selection of feathers
- A selection of massage balls so that the pupil can experience the feeling of pressing them against arms or legs, hands or feet or front or back or sides of the head.

Pupils spent two sessions quietly exploring each area with the lights kept low and music playing softly in the background. They were encouraged to roll about and cover themselves in the materials. While lying in the chosen area, support staff encouraged pupils to feel the sensations, smells, sounds and talk about how it made them feel. What did it make them think of? How does this place look, smell and feel like? They then made their preferences. We wrote a visualisation story based on the answers and words of each pupil. Some of them were quite imaginative like the one I will read to you. Some are descriptions of the experience like being in the tent, the soft walls, the smell the sounds and what it feels like to lie down in the tent.

The pupils would go to their chosen station to relax and

listen to their visualisation. In time, they just had a piece of material from that area to de-stress and listen to their story. They learned this strategy so that they could go to their happy place, in their mind any time of the day or night. Any time stress levels rise and they need a tool to manage. Here is John's happy place. He likes to cover himself in fur and listen:



John has now moved into his own special place. It is a nice, quiet, hairy cave. John likes it because it is dark and quiet and it makes him feel happy. He is relaxing and lying down in his hairy cave. It feels warm and furry. It smells nice. John's hairy cave is near the sea. He lies there in the soft, warm furry cave and listens. John can hear the waves from his hairy cave. He can hear the water and the

rocks in the sea. They make a rumbling sound. John likes to lie down in his cave and listen to the sounds. It makes him feel happy. It makes him feel safe. John thinks, "I like my cave". John lies quietly in his cave for three minutes. He is just feeling the fur and listening to the sea. John feels safe. He feels happy.

Now it's time for John to leave his cave. Take a deep breath and start to come out. It's time to come back to the gym hall again. But remember, whenever, you want, whenever you feel like it, you can close your eyes and come back to your warm, safe, hairy cave...

Another successful strategy involves Tai Chi. All pupils can access Tai Chi in their own way despite any physical constraints. The key to Tai Chi is breathing – slowly, deeply and rhythmically – as in the start of each Mindfulness session. The Tai Chi exercises we used make use of what we call the 'Five Treasures'. These are breathing and movement exercises designed to harmonise that slow gentle movement and deep relaxed breathing. The original aim of the Five Treasures was to draw Qi or Chi energy from the stars, the sea and the earth and also to give Chi or share it with others. We adapted the movements to take account of disabilities but have retained the principle of concentrating on harmonising deep breathing and rhythmic movement. This is a key technique which brings increased focus on the moment and the sense of emotional stillness which is the essence of mindfulness.

Some pupils are hoisted out of their wheelchairs on to a

beanbag or a mat for Tai Chi. Some only have slight control of their head and arms but take part in this practice very successfully. On a sunny day, we often take a quiet mindful walk out to the sensory garden and practice Tai Chi under the trees, whether standing or from a wheelchair.

The pupils feel the leaves above their heads as they stretch. In the silence, they have a heightened awareness of sounds, smells and nature.

Being outside and having this awareness of nature leads on nicely to what we call 'Journey' work. As we walk outside to the sensory garden, we help pupils to spend time becoming mindfully aware of the environment in which they are walking. They are encouraged to stop; listen to the sound of the wind; think about how it feels on their skin. They are encouraged to touch and explore the texture of the grass, leaves, soil, the trunks of the trees and so on. They actively listen to the sound of the birds in the garden and of the running water there. The pupils are experiencing 'just being in the moment' with whatever sounds and sensations surround them. This practiced focus on the now means that pupils can more easily recall the journey when back inside. Or I can take them on that journey on another day going through in detail every step, sound and sensation that we experienced. The pupils really engage with this; their favourite part of the journey shows on their faces with a smile. (e.g. passing the button for the lift – but not pressing it – Ciaran). Knowing that the pupils are reliving the journey successfully means that there



“This work can help develop empathy and enable a deeper understanding of emotions and techniques which involve mindfulness based cognitive therapy.”

is the possibility to add other imaginative dimensions. Like, “Now you are going to lie down in the grass, feel the grass all along your back, feel the warm sun on your face and go to your happy place/ hairy cave for example”.

From here we can also start to explore moods and emotions and begin to develop strategies to help the pupils be in more control of this. We have done some work where an animal or pet comes to sit beside each pupil on the grass. Or they curl up beside them and cuddle in. The pupils love this and afterwards talk about what animal was there and how happy it made them feel. Often deceased pets come back to life for this and pupils tell stories that make all of us smile.

We are now starting year 4 of the Mindfulness Program and our pupils have benefitted way beyond expectations. For the first six months, it looked like very little was happening and I began to question the validity of the whole program. I probably would have given up if I had the choice. I now realize that just because I didn't see it didn't mean it wasn't happening. A lot was

going on in the minds, brains and bodies of our pupils that didn't become clear for months or perhaps even a year. Mindfulness based stress control has a very definite positive impact.

Staff and parents observed that many of the pupils are self-regulating which has a major impact on transitions throughout the day. One mum got in touch with us as she couldn't quite believe that her son had self-regulated his distress out in a shopping centre. He had gone from the edge of the 'red zone' to telling himself “breathe now... breathe now...relax...relax”. More effective breathing is having an impact on their health, concentration and ability to learn, which teachers across the school have observed. Some pupils are finding fun, joy and a relaxed contentedness that had not been witnessed in these pupils before. They are quite simply happier. (The boy I mentioned earlier who is blind with autism is a different boy!)

The program has proved its credibility and our pupils can now draw on the techniques they have learned to control stress, help with flare ups of

anger and feel more relaxed. This year we will run sessions most mornings in school for pupils, after school for staff and hope to expand to parents and carers this year. We continue to develop the range of strategies that envelop mindfulness based stress reduction – Tai Chi, yogic breathing and, meditative visualisations. This work can help develop empathy and enable a deeper understanding of emotions and techniques which involve mindfulness based cognitive therapy.

The response has been so positive that we are creating a resource base from which people can take ideas, examples of visualization scripts specifically created for Visually Impaired people and recordings of meditations to use in different times and circumstances through the day.

For more information, contact Aine Murphy (aine.murphy@royalblindschool.org.uk), Principal Teacher/ Drama/ Mindfulness, Royal Blind School, Edinburgh, Scotland

CHARGE Network

Andrea Wanka reports:

We are now 80 members representing 17 countries in the DbI CHARGE Network. Anyone reading this and interested in becoming a member, please contact me.

Don't forget our preconference on September 4th, 2017 in advance of the DbI European conference in Aalborg/Denmark. We are charging a fee of € 55.

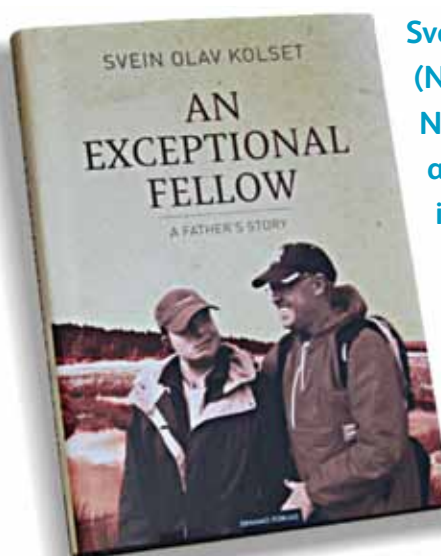
See the agenda in this report. Andrea is the contact person, so please advise her by email if interested in attending or presenting a paper.

Please look at the new CHARGE Network subsite on the DbI website: <http://chargenetwork.deafblindinternational.org>. It is our intention also to register as well on our website link.



For more information about the CHARGE Network please contact Andrea Wanka: aw@andrea-wanka.de

“Please look at the new CHARGE Network subsite on the DbI website: <http://chargenetwork.deafblindinternational.org>.”



Svein Olav Kolset (Norway) offered Network members a free copy of his impressive book “An Exceptional Fellow¹” which many took advantage. A big thank you to Svein from the DbI CHARGE Network!

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¹ anexceptionalfellow.com/the-book

Voices from the CHARGE Network:

A Parent Report of Potential Communicative Acts by their Children with CHARGE Syndrome

From Dr. Susan Bashinski:

A study conducted during the 12th International CHARGE Syndrome Conference (Chicago Illinois USA, July 30, 2015 – August 2, 2015) described the communication abilities of children / young adults with CHARGE syndrome, who have little to no natural speech and communicate primarily without the use of symbols (i.e., functional use of fewer than 50 spoken words or signs). Family members of 27 individuals (ages 17 months – 28 years) were interviewed by members of a research team headed by Dr. Barbara Braddock and Dr. Susan M. Bashinski. Families were asked to report on their child's use of potential communication signals – signals interpreted by family members as meaningful

communication. The primary data collection tool was the Inventory of Potential Communicative Acts (IPCA), J Sigafos, G Woodyatt, D Keen, K Tait... – Communication..., 2000 – cdq.sagepub.com.

The most commonly reported communication forms included: acting on a person¹ (27 participants), acting on an object² (26), moving towards a person/object (26), and crying (25). From families' reports, all participants utilized some communication forms involving multiple forms or activities. The mean number of diverse communication forms reported in use was 36.37. All 27 families provided information that documented their children using communication to: draw attention to self, reject or protest, request

an object, make a comment, and make a choice. Twenty-four of 27 children's profiles demonstrated use of communicative functions in 9 of the 10 IPCA categories. Requesting information was the least used, i.e 16 of 27 families reporting.

Participating families have done a noteworthy job of establishing a pattern of communication for their children with CHARGE. By attributing communication value to a child's / young adult's existing communication repertoire, educational teams can be encouraged to hold higher expectations, structure nonsymbolic communication intervention, and engage in more challenging communication teaching with these learners.

CHARGE Clinics

From Dr. David Brown:

One of the exciting changes in the CHARGE field recently has been the move towards developing CHARGE clinics where families can relate to multi-disciplinary medical teams who have a particular interest in the syndrome and familiarity with the issues it involves. Given the great difficulty families face in finding professionals familiar with the syndrome, this is an exciting development which needs to be encouraged. In the United Kingdom Dr Jeremy Kirk has been gradually developing this concept in Birmingham over the past few years, and now we hear of another CHARGE

clinic being created in a hospital in Manchester. In the United States the Cincinnati Children's Hospital has a very successful CHARGE clinic which is attracting families from a very wide geographical area of the country. On October 14th, 2016, the hospital will be holding its first one-day CHARGE conference with presentations from a variety of specialists. The following day individual consultations will be offered to families who have attended the conference on the previous day.

On October 1st, 2016, Dr Daniel Choo, (Director, Division of Paediatric Otolaryngology – Head and Neck

Surgery, Professor, UC Department of Paediatrics, UC Department of Otolaryngology – Head & Neck Surgery Cincinnati Children's Hospital, USA) will present "General ENT and audiological development in people with CHARGE syndrome" at the Australasian CHARGE Syndrome Conference on the Gold Coast, Queensland, Australia. (<http://www.chargesyndrome.org.au/events/the-12th-biennial-australasian-charge-syndrome-conference/the-program/>)

It would be interesting to hear if any other hospitals have embarked on these kinds of developments in other countries.

¹ Examples of acting on a person include: taking hold of another person's arm, pulling on a parent's leg, or otherwise attempting to manipulate another person's body.

² Examples of acting on an object include dropping an object to the floor, throwing an unwanted object, handling a desired object, etc.

Outdoor Network

Joe Gibson reports:

The main event since the last report has been this year's DbI Outdoor Network week. This year the event was held in England for the first time. It was the largest meeting so far with a total of 21 deafblind adults, supported by a team of 40 support staff, siblings, parents and relatives who came together at The Calvert Trust site based in Exmoor¹. The event was co-ordinated this year by Jon Fearn from Sense, based in Birmingham, England and the participants came from Scotland, Norway, Denmark, Holland, Sweden and from all over England.

Working in 6 groups of 10 people each day, the participants took part in a series of exciting activities included climbing, abseiling, sailing, horse riding, cycling, and a zip wire. There were also activities based in the forest, which involved woodland exploration, lighting a fire and cooking. There was a really positive atmosphere throughout the week, with people making new friends, and supporting each other as they tackled some new challenges and experiences. The event generated a lot of outside interest, which included a film



crew coming along from the local TV station to capture and showcase this International event.

The list of members of the Outdoor Network continues to grow with 107 people from 25 different countries registered on the mailing list. You can join the mailing list by send an e-mail to Joe Gibson at deafblindoutdoors@gmail.com The Outdoor Networks Facebook page is an active way that members share stories of what they have been doing and what they plan to do. You can find and join the Facebook page at <https://www.facebook.com/groups/771554296237459/?ref=bookmarks> or by searching for Outdoor Network, Deafblind International.

Joe Gibson
deafblindoutdoors@gmail.com

¹ www.calvert-trust.org.uk/exmoor/exmoor



Usher Network

Emma Boswell reports:

Well, 2016 has gone so quickly with 2017 almost upon us. The six strong committee members of the Usher Network have maintained their enthusiasm and worked hard to keep on inspiring. A big thank you!

Pre-conference Announcement and calls for Expressions of Interest

We are very proud to announce there will be an Usher Network Pre-conference to be held in Aalborg Denmark on Sunday and Monday, September 3rd and 4th, 2017. This will provide a fantastic opportunity for people to share ideas and network within the sphere of the Usher community.

First, a brief background of the Usher Network. An Usher study group was first established in 1985, through the efforts of the late Mary Guest, with the aim to get medical and Usher professionals together as part of an international network. The study group organized meetings through the years, eventually organizing pre-conferences attached to major DbI related events such as the 13th DbI World Conference in Mississauga Canada (2003); the 14th DbI World Conference in Perth Australia (2007); the 8th ADbN Conference in Aalborg, Denmark (2010); the 9th ADbN Conference in Lund Sweden (2012) and the 10th ADbN Conference in Belfast, Northern Ireland (November, 2014). Note that since 2014, the Usher Study Group has been renamed the Usher Network.

Quite recently, Karen Wickham, one of the Network committee members, recently organized an event (run by both Senses Australia and Deafblind International Usher network) prior to the Australian National Conference held in Fremantle, (near Perth) Australia. This fantastic event galvanised the Usher community with huge success. See Karen's report on this preconference in the Australia section of this current edition of DbI Review.

Thanks to the success of all our network events we know that the opportunity for professionals, families and people with Usher to get together is a very rare but hugely important and valuable exercise. Having Usher syndrome can be very challenging with people experiencing emotions close to a bereavement on diagnosis, and experiencing isolation as their vision/ and or hearing deteriorates. They face changes in their communication methods, which may involve them making life changes. Yet with the right support, people with Usher can overcome the potential barriers their condition may create, taking advantage of adjustments and adaptations to achieve success. Many people with Usher will achieve important milestones in their life.



The theme of our next Network preconference is 'Building Blocks of Social Connectivity' run in conjunction with the 9th DbI European conference: 'Touch of Closeness – Maintaining social connectedness'. We will focus on several speakers from the genetic and psychological disciplines as well as personal stories to highlight what it is like living with Usher. If you would like to give a presentation, or are interested in facilitating one of the café style networking slots, please contact me. Or you can just come and join us for the Usher Network Pre-conference. Contact me for more info at: emma.boswell@sense.org.uk

More details can be found on the Usher Network section of the DbI website: www.usher.deafblindinternational.org

We would like to increase our membership community. To join the network please contact us at the same email address above.

For more information, contact Emma Boswell (emma.boswell@sense.org.uk) or Najda Hoegner (najda.hoegner@googlemail.com)

“Yet with the right support, people with Usher can overcome the potential barriers their condition may create, taking advantage of adjustments and adaptations to achieve success.”

Research Network

Walter Wittich reports:

As the DbI Research Network is moving through its second year of existence, we continue to grow and expand. As of October 2016, we now have 101 members on our e-mail contact list.

Saskia Damen and Flemming Ask Larsen continue the maintenance of the Deafblind International Research Network – Facebook Group¹, currently at 150 members and growing. Come look us up and join in the conversation! Christine Lehane continues to maintain our Deafblind International Research Network LinkedIn group², currently with 42 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.

In the context of research distribution and dissemination, a very exciting resource has come to our attention, thanks to Claes Möller and his team at the School of Health Sciences at Örebro University, Sweden³. In case you want to access over 3,200 publication summaries and articles about the topic of deafblindness, please visit the Research Overview page of the *Nationellt kunskapscenter för dövblindfrågor*⁴, based in Lund. The searchable database is available



with both an English and Swedish interface, and will provide you with access to a large variety of relevant information: <http://nkcdb.se/research-overview/>

The Research Network is proud to report that Deafblind International is co-sponsoring two research panel presentations at the 12th International Low Vision Research and Rehabilitation (ISLRR) Congress⁵ to be held in The Hague, Netherlands, from the 25th to the 29th of June 2017. Walter Wittich will host both the panel on congenital and on acquired deafblindness, and will be proud to introduce several members of the Research Network as presenters, including Jude Nicholas (Norway), Susan Bruce (MA, USA), Marleen

Janssen (Netherlands), Susan Bashinski (MO, USA), Mijkje Worm (Netherlands), Saskia Damen (Netherlands), Bernadette Gavouyere (Quebec, Canada), Karen Keyes (Ontario, Canada), Alana Roy (Australia), Ton Roelofs (Netherlands), and Peter Simcock (United Kingdom).

If you have any ideas for us, or 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 and contact us with your interests and thoughts.

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

“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.”

¹ <https://www.facebook.com/groups/158743377516989/>

² www.linkedin.com/groups/8339092/

³ <https://www.oru.se/english/schools/health-sciences/>

⁴ www.anhoriga.se/.../nationella.../nationellt-kunskapscenter-for-dov...

⁵ www.islrr.org/

Communication Network

Ton Visser reports:

September had been a busy period for the Communication Network. Our last meetings were focussed on preparing for the upcoming conference 'Communication in the context of congenital deafblindness'. We are very happy that we will welcome many of our colleagues in Groningen, November 15–17, 2016. We are pleased that we will welcome a number of participants from outside Europe as well.

This conference is organised to celebrate ten years of the International Masters of Education and Congenital Deafblindness course. The alumni of the University of Groningen Masters program played an important role in preparing the program and will also take the responsibility delivering an

important part of the program during the conference. It is great to see how many of the alumni created such a strong network with their alumni colleagues after their study at the university. How easily they find each other when needed. Sadly, I have to report that after the conference Inger Rodbroe and myself will leave the Communication Network.

This past September the University graduated 8 students around the same time that we started the 11th year of the Masters Program. The 10 new students began by following an intensive 4 week lecture program given by members of the Communication Network. Like each group in the past, the individuals completed their four week program with a proposal for their master thesis



including discussion with the lecturers about their proposal.

In March 2017 there will be an evaluation of the Masters Program after ten years. The results of the ten year evaluation will appear in an upcoming edition of DbI Review. I should also point out that, while the articles are ready for the Second Edition of the Open Access Journal, unfortunately we have to postpone publication until the review process is completed.

Ton Visser

Email: asmvisser1948@gmail.com

Youth Network

Simon Allison reports:



A total of eighteen Youth Network members attended an activity at Disneyland Paris in September 2016. Countries

represented included Russia, Norway, Scotland, Finland and England. Members stayed at both the Hotel Cheyenne and Hotel Santa Fe.

The young people enjoyed each other's company in exploring the two Disneyland parks, taking in the many rides and Disney shows. A favourite was the Disney street parade and the illuminated Castle firework display. This made for some

very late nights which was all part of the fun. Some of the members also visited Notre Dame and the Eiffel tower during an evening trip to Paris.

The event also included a short program of workshops in which the young people could socialise and make some new friendships. A highlight was a workshop in which the young people explored both the similarities and differences in their signed communication. A map of the world was also created charting the journeys the young people had made to get to Paris.

On the final day there was an opportunity for the young people to network and present information on the services in their respective countries. There was also discussion

about the Network pre-conference planned for Aalborg in early September 2017. Further details about this will be on our network link on the DbI website: <http://dbiyn.deafblindinternational.org/>

Network member Grace Maltwood from England commented on her Disney experience "This was my very first trip to another country. I enjoyed it so much I wanted to stay a bit longer. I made plenty of new friends in particular Maria from Norway who I plan to keep in touch with and maybe meet again at another network activity".

For more information contact Simon Allison, Network coordinator: simon.allison@sense.org.uk

Youth Network: Trip to EuroDisney

September 27–28, 2016



Frank Kat (Treasurer and VP of DbI) and myself, a trainee at Kentalis, were invited to accompany the DbI Youth Network on a special adventure. What better place for this group of disabled people to visit for a lifetime experience but there to go to then Disneyland Paris.

We left from Kentalis in Sint-Michielsgestel in the early afternoon for a 5+ hour drive to Disney. This gave me sufficient time for me, as a new trainee, to learn more about Kentalis, and especially develop an understanding about this special group of people with deafblindness, individuals that I had never met. I was a bit nervous about this new experience.

After a long drive in heavy traffic we arrived at our hotel at Disneyland. Our next step was to find the group and get to know them. We first met Andy Kerr (Sense Scotland) and their group of ten deafblind individuals (ages 15–22) and their accompanied supervisors. We spent an enjoyable evening communicating with the group.

We had an early start so as not to miss anything at the park. But before entering the park, we participated in a workshop session, coordinated by Simon Allison,



(Youth Network Leader) where leaders from Able Australia, Kentalis and Sense Scotland described their programs for people with deafblindness in their country.

During this session, it was very special for me to observe the youth from the various countries communicating with their individual sign language and detect some of the similarities and differences. For example, the Dutch sign language for soccer was quite similar for being drunk in the United Kingdom.

Simon also had a workshop to encourage individuals to eliminate their fears.

An example was to first write your biggest fear on a wooden board. When you were ready to conquer a

fear you needed to break through the wooden board which was similar to karate.

After the workshops the large group was split up into smaller groups before entering the park, largely based on nationality. The groups were as follows: from Scotland (a group of 19, 10 individuals with deafblindness and 9 supervisors); from Russia (a group of 5, 3 with deafblindness and 2 supervisors); from Norway (a group of 3, 1 with deafblindness and 2 sign language interpreters), and from England (a small group of 2, 1 with deafblindness and 1 being a sign language interpreter).

In the park, our group first visited the very accessible attraction Buzz Lightyear, which everyone enjoyed a lot. After a few other attractions, the groups attended the final attraction, Mickey and the magical show. This event provided a great deal of interaction opportunities for the individuals. After the Mickey Magical Show, probably the most favourite of the day, everyone being quite tired after an exhausting day went back to their hotels and dinner before retiring for the night before their long trip home the next day.

**Prepared by Quillen Govers,
Kentalis Trainee**



The importance of the bodily-tactile modality for students with congenital deafblindness who use Augmentative and Alternative Communication (AAC)

Kirsten Costain Schou¹, Torill Gullvik² and Gøran Forsgren³



Kirsten Schou



Torill Gullvik



Goran Forsgren

The study of the bodily tactile contribution to language development in students with congenital deafblindness (CDB) is an emerging field (Dammeyer & Nielsen, 2013). In work with these students, the bodily-tactile modality is essential for the development of understanding, conceptual learning and cognitive abilities. For individuals with CDB, shared touch and motion with their communication partners are the primary means for attachment building, joint attention and communication (Nafstad & Rødbroe, 2008, 2015; Ask Larsen, 2013). This modality involves much more than a simplistic notion of tactility as limited to basic touch focused on the hands alone (though “touch” is in itself a vast and highly complex topic, and tactile communication involves far more than mere “hand-over-hand” signing; Buelund Selling, 2013). Rather, the bodily-tactile modality involves an eclectic, bodily approach to the whole child as a physical individual in a physical world. The physical

approach also includes the residual senses (vision/hearing) and the entire body. Use of tactual signs/sign support based on elements from Norwegian Sign Language as well as haptic communication are part of, but not the full extent of this modality. Maintaining contact between the child and the physical world is essential for development of both language use and cognition. The increasing number of children with congenital deafblindness who also have additional (multiple) disabilities makes this even more of a challenge, and no less important for the adults who support and work with them.

Children with congenital deafblindness have, in

common with other children, youth and adults who completely or partially lack functional formal language, the need for alternative and/or supplementary forms of communication in order to make themselves understood. Persons with congenital deafblindness generally have little or no understanding of what others say when communication is based solely on vocally expressed language. These people belong to the group of AAC users with differing forms of sensory loss in that they have a combined visual and hearing loss of varying degrees of severity. Although all the students have the functional description known as congenital deafblindness, there can be great variation



School students with congenital deafblindness and AAC

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among individuals with regard to education and training in and with AAC. Many students have motor difficulties that lead to reduced mobility and compromised movement, which in turn lead to the need for help in moving about in the world from place to place, in making use of helping aids and/or in performing motor actions and functions. At the School⁴, teaching is performed in the most appropriate communication form(s) available, adapted to the child's limitations, and with a basis in the creation of opportunities to develop functional communication and linguistic development.

At the School, the teachers facilitate the construction of individual and adapted solutions to these challenges with a central focus on the tactile modality, including the use of tactile reference symbols and the tactilization of signs. The spontaneous expressions in communication (viewed as possessing linguistic qualities) of the students, their way-of-being and bodily expressions in general are accorded a communicative intention by the teacher. An attempt is made to interpret these with reference to the here-and-now as well as to knowledge of the student's experiences in other arenas and in the past.

Tetzchner and Martinsen (2002) divide people with need of AAC into three main functional groups. This division is based on the function AAC is intended to have for the individual, whether in terms of a means

of expression, a support language or an alternative language. Persons with congenital deafblindness will primarily belong to the *group with need of an alternative language*. Many people with combined sensory loss have residual vision and/or hearing. Those with residual hearing can develop more or less understandable vocal speech, and/or can understand the speech of others if it is supported by tactile symbols, tactile signs or pictures. It is thus possible to locate these students in the *expression support group*, or the *linguistic support group*.

In order for the students to gain access to an appropriate or most effective form of communication, the work is on two levels at the same time:

- Investigation of how the individual student can gain the opportunity to express themselves in the best possible way, and
- Facilitation and construction of an environment/arena in which all students can have the opportunity to understand and be understood.

As mentioned above, use is made of tactile signs and gestures, tactile symbols, photographs, graphic signs, objects, data-technical aids such as the Sarepta program⁵ and various iPad⁶ programs. Much time is used at the School to create communication systems and learning aids adapted to the needs of the students, as there is little ready-made material available.



In the teaching, teachers are concerned with maintaining a focus on dialogue and access to competent communication partners. These are the foundational elements in everything they do together with the students.

The bodily-tactile modality in supporting children with congenital deafblindness

Blind children with CDB are especially dependent on their partner's ability to interpret the world for them by sewing together contexts to which they otherwise do not have access, through haptic and mobility-based (among other sources) forms of information. Access to context is nevertheless a main challenge for all children and adults with congenital deafblindness. Bodily-tactile experiences with the physical world are an important part of giving them this access, and thereby helping them build up the contents of their conceptual apparatus, which can otherwise remain extremely abstract and impoverished. Through experiences with interaction between the child's physical

⁴ www.statped.no/spraksider/in-english

⁵ www.icevi-europe.org/dublin2009/ICEVI2009_Paper_121.doc

⁶ www.apple.com/ca/ipad/

Importance of bodily-tactile modality

self and the rest of the world (including the teacher/ other), certain mental schema are constituted over time. These can be called *gestalts*⁷. A *gestalt* is “an organized unified whole within our experience and understanding that manifests a repeatable pattern or structure (...) experiential *gestalts* have internal structure that connects up aspects of our experience and leads to inferences in our conceptual system” (Johnson, 1987, p. 44). The manner of this constitution and inference-making for the individual is through repeated experience and embodied action on, in and from the world of physical, emotional, social and cultural experience. By bringing the physical world to the child through interpretation (based on touch and bodily engagement), and information (through tactile communication forms, contexts and actions) become clarified for the child, along with the presence and roles in these contexts of other people. Tactile and bodily-tactile information can prevent the kinds of breaks

or ‘breaches’ in action sequences and contexts that can otherwise create chaotic and haphazard experiences for persons with congenital deafblindness.

Increased bodily-tactile information increases understanding of the physical environments in which the child lives, and this understanding in turn facilitates a greater feeling of belonging within the physical-cultural context. The bodily-tactile *inclusion* (also, beyond the mere use of tactilized signs) of the person in interactional contexts can reduce feelings of isolation as well as support the agency of the person (Nafstad, 2015). Bodily-tactile inclusion means that the person is in physical contact with the context and the (co-produced) actions occurring in it in a participative bodily manner adapted to their needs and prerequisites for such participation.

Being able to understand how actions lead to results in the course of the many practical actions and tasks that comprise much of everyday life is difficult for persons with congenital deafblindness. Their inclusion in a bodily-tactile manner in such tasks and activities (instead of only or primarily being acted-upon or around by helpers) creates opportunities for the person with CDB to experience their own ability to act on the world. Agency, or the understanding that one’s actions have consequences, that one can influence one’s surroundings (Goldbart,

2015) is one of the most important conditions for learning. This understanding increases in accordance with the understanding of how things (interactions, actions and activities) arise and are connected in each context before they disappear again and something new is begun. Being able to gain insight into this process through inclusion in the physical world of objects, actions and relationships in a way that is felt by the body is to *know* that one is included, rather than merely being told that one is. A crucial aspect of access to context is thus also access to participation in cultural contexts (Nafstad & Rødbroe, 2008, 2015; Ask Larsen, 2013) that are also, always, physical. This participation, then, needs to be bodily-tactile (that is, physical in the extended sense of focus on whole-body presence), genuine (the person actually *is* physically participative in the cultural activity), and engaged (part of the bodily-tactile modality is the emotions and their bodily expression).

The hands (and the body) are always there

Children with need of support systems for expression and communication often use several forms of such support. There have been great developments in the field of AAC, both in terms of access to and opportunities for choice of technical communication aids. It appears however that there are still many challenges remaining with regard to



⁷ www.thefreedictionary.com

access to such aids and adequate follow-up to ensure that their use has good and lasting effect (Mirenda, 2014).

One example of such a challenge is maintenance of regular use of communication tools and systems when a child becomes an adult and moves into a residential setting. Hamm and Mirenda (2006) point out that lack of follow up of use of technical communication tools after schooling is completed is a well-known problem in the AAC field with roots in both practical and policy barriers. Several studies within the field confirm that good quality of life is equivalent to good quality of communication (Hamm & Mirenda, 2006; Lund, 2001; Slesaransky-Poe, 1997). It is also clear that even though technology can be wonderful, it cannot solve every problem (Lund, 2001, p. 108 cited in Hamm & Mirenda, 2006). Technical tools require supervision, instruction, follow-up and maintenance, and these are not always as available outside of the educational setting.

When we look at tactile communication as one of the alternatives to vocal speech, we see several clear advantages. Tactilized signs and haptic communication of information are always-available means by which to communicate, and tactile communication forms make it easier to communicate continuously and to maintain a communicative focus in all the situations of daily life. Tactile communication is also much more than use of the hands to communicate, and includes basic touch, and the kinesthetic (movement) and

proprioceptive (muscular-sensory) modalities (Buelund Selling, 2013). The tactile modality in general is also part of strengthening the person's relationships with other, more technical forms of alternative and augmentative communication. Establishing and maintaining good and consistent use of communication systems based on picture cards and other symbols for example, is dependent on the motivation of the communication partners, and follow-up is thus extremely vulnerable and individual-dependent. The hands and body are always present however, and communication accordingly is always important, regardless of absent technical support there-and-then. Communicative relations have to do mainly with communicating with persons, not systems; a bodily-tactile approach can provide physical proof of the truth of this focus, that the person with congenital deafblindness is the primary focus, and not the communication system in itself. This combination between tactile modality and other communication tools can provide an optimal solution.

Maintaining the flow in communication is based in large part on being able quickly to perceive and understand, answer and engage oneself as a communication or support partner in communication with other people, and this is even more important in communication with people who have little or no formal language. A bodily-tactile approach provides many opportunities



for quick response and confirmation of the person as a communicative being. Body language that has meaning for communication partners, both those with and those without congenital deafblindness, can include everything from eye-blinking to positioning of the whole body, pointing with different parts of the body including the hands, and all forms of movement and acceptable bodily contact between the parties. A rich register of possibilities for interpretation and communicative contact with the person with congenital deafblindness can be revealed if the partner takes a diverse and varied approach to communication and understanding based in the bodily-tactile modality.

Face-to-face communication is always vulnerable and must be borne through the frequent difficulties and breaches, lack of understanding, misunderstandings and other challenges that are common for all communicators but especially challenging in the case of congenital deafblindness. It is the intention of the communication partner expressing towards the person with CDB, to communicate, understand and most importantly, to see the

Importance of bodily-tactile modality

person as a worthy subject, that keeps communication moving. This intention, when expressed well, makes the partner appear to be one who listens and tries to follow the person's expressions rather than one who is primarily a decoder (Nafstad, 2015). Through listening and following expressions also in a bodily-tactile manner, even without understanding them, the partner provides acknowledgement that the bodily and bodily-symbolic expressivity of the person with CDB *is* the person's own voice (Nafstad, 2015). One who experiences themselves as seen and treated as a worthy and communicative subject can more easily tolerate difficulties and setbacks in communicative situations, and can more easily stand in the tension between being self-directed and being directed toward the other, even when the distance between these different perspectives is great (Nafstad, 2015).

Not one or another, but all means of communicative practice

For the communication partner of a person with complex communication needs, it can be very easy to worry over not being faithful to or disciplined enough with regard to the use of one or several main communication tools or systems, such as pictures, graphic symbols, tactile reference objects, voice synthesis and so forth. It can also be the case that the goal that supportive others have for the child, of acquisition of a formal cultural language, locks communication with the person to a more or

less exclusive focus on, for example, formal cultural tactilized signs. It is in any case clear that people with CDB have need of several information channels as the distal senses are lacking or severely limited, and that the tactile sense in the broadest sense is the most primary of all the sensory channels (Nafstad & Rødbroe, 2015). Studies of language acquisition have begun to focus to an increasing extent on multi-modality in language-in-use: that is to say, away from a one-sided focus on (so-called) verbal language, and toward a focus on the multiplicity of linguistic *practice*, in which also body use and prosodic (rhythmic, sound) elements are involved (Dufva, Aro & Suni, 2014). Language is not so much acquired as lived in and through and as such is part of our embodied being in the world. The bodily-tactile perspective must not be viewed as in any way incompatible with the use of augmentative and alternative communication systems, but rather as part of the rich repertoire of linguistic-communicative practice in which such systems participate.

The bodily-tactile modality is a bridge-builder between several communication forms and channels. In addition, it creates a continuity in the experience of the person with CDB of the presence of partners, and of being an integrated part of a physical and social context. Thus, a basis in a bodily-tactile approach along with a meta-perspective about what communication is, liberates partners to respond in a fluent way with touch and movement in a communicative dance with the person with CDB. Bunning (2009) states that "communication concerns two or more persons working together and coordinating their actions in a continued attempt to respond *to one another and to the context.*" (p. 48). Further, it can "(...) be intentional or unintentional, involve conventional or non-conventional signals, take linguistic or non-linguistic forms and occur through spoken or other modalities." (p. 48). This broader perspective on communication can support the partner in maintaining a general bodily-tactile way of being with people with CDB. Making use of haptic



and tactual signs in a playful manner, for example, when singing a well-known song or rhyme is a good way to build on and make a routine activity more interesting, and is something that can have significant impact on language development. Use of tactile sign support in addition to visually perceived sign language and vocally expressed language (when these are part of the flow of communication) does not need to distract from or undermine the other modalities. When distal sensory channels are weakened to the extent they are in CDB, any addition channel is likely to have a strengthening effect on understanding in communication rather than being a distraction. A more spontaneous use of bodily-tactile modes of communication and remaining in touch in the course of communication and participation can support other modes during their use.

Lastly, but no less importantly, supporting through the body-tactile modality should never be confused with creating dependency, or depriving the person with CDB of the opportunity to move out into the physical-social and cultural environment on their own. Through taking a bodily-tactile approach to, for example, mobility training, the person can be introduced to the physical environment and the task of moving herself around in it through application of techniques, and gradually move toward greater independence and spontaneity in this movement. In addition to enlivening

the teaching of mobility, a bodily-tactile approach to this teaching combines learning the *techniques* involved in this skill with the kind of embodied phenomenological accompaniment of the person by the partner that underscores the primacy of the *learner* herself in the learning. Part of both learning and motivation for learning is being able to understand the reason for learning something. The bodily tactile modality can be used to show the function of skills enactively as the partner provides a bodily-tactile scaffold for learning which demonstrates their purpose at the same time as modelling the skills in an immediately relatable way to the learner with CDB. Ultimately, the central reason for learning skills and developing competencies is access to opportunities for a richer experience, and a richer quality of life.

Conclusion

With the condition that there are sound intentions and respect for the person's own boundaries, a rule of thumb for the partner is that it is not possible to make mistakes in the attempt to make contact and come into a communicative position with a person with congenital deafblindness.

Having a playful and open relationship to the bodily-tactile approach is part of supporting communicative competencies under development, and contributes to keeping the focus on the communicative project. It provides emotional and moral support (through showing and being a concrete experience of inclusion) as



well as the experience of confirmation of oneself as a communicative *subject*, a person with communicative intentions and aims. This experience is fundamental to the maintenance of the motivation to learn, and to use language. The bodily-tactile modality is a foundation for relations with persons with CDB and is part of the unification of the often fragmentary or dissolving and, sometimes, chaotic experiences such persons have in meetings with a primarily seeing and hearing world. As such, it is of great importance for communication and continuity, both for persons with CDB and for their seeing and hearing partners.

**For more information, contact
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References

- Ask Larsen, F. (2013). Acquisition of a bodily-tactile language as first language. In J. Dammeyer and A. Nielsen (Eds.), *Kropslig og taktil sprogudvikling*, Aalborg: Materialcentret, pp. 91–119.
- Buelund Selling, H. (2013). Tactile communication is more than visual sign-language hand-over-hand. In J. Dammeyer and A. Nielsen (Eds.), *Kropslig og taktil sprogudvikling*, Aalborg: Materialcentret, pp. 177–188.
- Bunning, K. (2009). Making sense of communication. I J. Palwyn og S. Carnaby (Red.), *Profound multiple intellectual disabilities: nursing complex needs*. London: Blackwell.
- Dammeyer, J. & Nielsen, A. (Eds.) (2013). *Kropslig og taktil sprogudvikling (Bodily-tactile language development)*. Aalborg. Materialcentret.
- Dufva, H., Aro, M. & Suni, M. (2014). Language learning as appropriation: how linguistic resources are recycled and regenerated. Lintunen, P., S. Peltola & M.-L. Varila (Eds.) 2014, *AFinLA-e Soveltavan kielitieteen tutkimuksia 2014/n:o 6*, 20–31.
- Goldbart, J. (2015). Forelesning: Pre-intentional and early intentional communication intervention. ISAAC Norge, 12. nasjonale konferanse 13–15 april.
- Hamm, B. & Mirenda, P. (2006). Post-school quality of life for individuals with developmental disabilities who use AAC. *Augmentative and Alternative Communication*, 22:2, 134–147.
- Johnson, M. (1987). *The body in the mind: the bodily basis of meaning, imagination, and reason*. Chicago: The University of Chicago Press.
- Lund, S. K. (2001). Fifteen years later: Long-term outcomes for individuals who use augmentative and alternative communication. *Dissertations Abstracts International (UMI No. 3036075)*.
- Mirenda, P. (2014). Revisiting the mosaic of supports required for including people with severe intellectual or developmental disabilities in their communities. *Augmentative and Alternative Communication*, 30:1, 19–27.
- Nafstad, A. V. (2015). Communication as cure: communicative agency in persons with congenital deafblindness. *Journal of Deafblindness Studies on Communication*, 1, 23–39.
- Nafstad, A. V. & Rødbroe, I. B. (2015). *Communicative relations: interventions that create communication with persons with congenital deafblindness*. Aalborg: Materialcentret.
- Nafstad, A. V. & Rødbroe, I. (2008). Kommunikative relasjoner: Innsatser der skaper kommunikasjon med mennesker med medfødt døvblindhet. Aalborg: Materialcentret.
- Slesaransky-Poe, G. L. (1996). *Consumer Survey on Communicative Effectiveness*. Unpublished manuscript, Temple University, Philadelphia, PA.
- Tetzchner, S.V. og Martinsen, H. (2002). *Alternativ og supplerende kommunikasjon: en innføring i tegnspråksopplæring og bruk av kommunikasjonshjelpemidler for mennesker med språk- og kommunikasjonsvansker*. Oslo: Gyldendal akademisk.



Gestures in Augmentative and Alternative Communication¹

Angela Camenisch², Monika Camus³ and Anita Portmann⁴

Children can communicate using their body from birth onwards. They use it to demonstrate the focus of their attention, to participate in games with others, to express their approval or disapproval and to let others know about their needs. And of all the body-parts, the hands are especially helpful and expressive. In a spoken language environment, healthy children soon notice that words are understood more quickly and by everyone they wish to relate to, which is why speech soon displaces hand-based communication. But if this development does not happen or is delayed, then the hands continue to offer an important way of developing communication. This is why gestures and hand signals are some of the most important techniques of Augmentative and Alternative Communication (AAC). In Switzerland Tanne⁵ is working on a new collection of gestures that will reduce barriers in communicating with persons with special needs.



(Left to right): Anita Portmann, Angela Camenisch and Monika Camus

Early communicative development

The development of speech in children begins straight after birth, when parents intuitively and playfully pick up upon and imitate the sounds and movements their child makes. This leads to the earliest dialogues, in which parents try to gain the child's attention and hold it for a while. When the child begins to show more interest in its environment, parents follow its gaze and movements, and include the object of its attention into their interaction with it. When they do this, parents adapt their speech to the child's

current ability to perceive things; the pitch of their voice becomes higher and more melodious, and a few words are repeated over and over, rather like the refrain of a song. They also use facial expressions, body language and gestures a lot, sometimes to support the things they say.

Shared body-games evolve in which the child uses movement to show what is going to happen next (see Papoušek 2001 117ff). This ability is demonstrated very nicely in the various knee-riding games that are widespread, such as 'Ryte Ryte Rössli' (a game in which

the child is bounced up and down on the knee to the words of a rhyme); by letting its body fall a fraction of a second before the fall happens in the rhyme, the child shows that it well knows and is able to anticipate exactly what is going to happen. Parents like to delay the moment of the 'fall' a little. This makes the game more exciting and it allows the child to take the lead, thus showing that it knows the next step.

As the child continues to develop, it begins to check whether the person with whom it is interacting is paying attention and looking at the object in which it itself is interested. This can be observed by the way a child looks to and fro between the object of interest and the person. This is how attention is first shared: the child and its

¹ The article was originally published in Switzerland in *Physiotherapia Paediatrica's* pp-Bulletin (<http://www.physiotherapia.paediatrica.ch>)

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⁵ Tanne (www.tanne.ch) is a small corporate member of DbI

Gestures in Augmentative and Alternative Communication



Fig. 1: Father interacting with his child

reference person both direct their attention to the same thing – and both of them are aware that they are not only looking at it but also thinking about it.

The next important step happens when the child becomes able to follow the other person's line of attention. It watches the person and looks in the same direction or towards the place where that person is indicating with a gesture of the head or hand. From the age of 13 months onwards, the child learns to direct its mother's attention to something else. Usually children do this with a gesture, by touching the mother or by verbal means (see Nonn, 2014).

Pointing gestures, conventional and iconic gestures

One very important communicative method which the child acquires at around one year of age is that of pointing. Pointing – which Tomasello (2014, p. 164) defines as “directing the attention to an object that is present” – can be used for many different purposes: as a demand – *Give me THAT!*; as information – *THERE is the*

ball!; to share experiences or feelings – *THAT was funny!* or *THAT hurts!*; to express a need – *I want to go THERE!*; and to express the child's own opinion – *I don't like THAT!* At around one year, children also learn the first spoken conventions (words) together with conventional gestures such as shaking the head as negation and waving to say goodbye.

Conventional gestures are established by society, widely known, and understood by everyone. Children learn these gestures by imitating adult reference persons, but they use them much less than pointing. At the same age, deaf children also learn the first conventional gestures of a sign language (see Tomasello 2014, p. 160). To name an object or indicate an action, children also use iconic, pictorial gestures. They depict the object with their hands or imitate an activity by miming it. Conventional and iconic gestures require certain skills of imitation, simulation and symbolic representation, and this places them at more or less the same level as words in their cognitive demands.

Tomasello (2014, p. 164–166) suspects that this is one of the reasons why they are used only for a short time and are soon replaced by the spoken words with which they compete. Pointing gestures, however, are not the same: drawing attention by pointing is very effective and does not compete with newly learned words, but instead can be combined with them very well. That is why the first complex statements often consist of a combination of a pointing gesture and a word: *DOG THERE!* Depending on the culture, widespread conventional gestures remain established in word-gesture combinations of this kind. They fulfil an emphatic, reinforcing function.

So it is clear that all children use different forms of gestures as they learn to speak. Some of these remain in combination with words, while many others are gradually superseded by words as language is learned, since it is quicker to communicate using speech in a spoken language environment where speech offers more opportunities for differentiation.



Fig. 2: Pointing is a gesture that remains important to all children

Gestures and signs for children with disabilities

If a child with cognitive impairment and/or multiple (sensory) disabilities is inhibited in its spontaneous acquisition of speech, then gestures continue to offer a means of communication. At the same time sign language can also be offered to the child to provide it with 'words' – based upon the normal progression of speech acquisition. The gestures of sign language represent conventional indicators just like the words of a spoken language, and offer the same opportunity to achieve an intended effect with other people. In AAC with hearing people, gestures are always used to support spoken language. That means the appropriate gesture is offered together with words that carry meanings. Children with disabilities often have serious difficulties understanding spoken language. Gestures visualise the language, supplementing the auditory perception of the words using the visual channel of perception. This makes understanding much easier. Apart from that, people using gestures speak more slowly, articulate their words more clearly and structure their statements better. All of these factors increase the child's chance of understanding what is being said. The linguistic system of reference is always the spoken language. That is why people's anxiety that children who use gestures will not learn to speak is unjustified and has long been disproven. This is because children with disabilities use spoken language in a spoken environment as soon as they



Figures 3 and 4: Teachers using gestures with their students

are able to make themselves sufficiently understood by doing so. In summary it can be said that the early use of gestures not only assists the understanding of speech and a child's communicative capability, it also promotes the production of speech (Nonn, 2014, p. 65).

Gesticulation has a number of advantages over other forms of augmentative and alternative communication. Gestures are produced naturally by the body and are always available, so they can be used quickly and spontaneously in every situation – such as in a swimming pool. Two people who use gestures to converse are in a natural communicative

situation: they face each other and have eye-contact and their attention is directed at one another and not at an image, a board or an electronic device. This not only makes it easier to pay attention, it also makes emotional contact and the exchange of feelings easier, since they are 'written in the other person's face'. Feelings are also expressed immediately in the way gestures are performed, just as they are in speech through the tone of voice, volume and speed of delivery. Because both communication partners are using the same mode of communication, that communication is more likely to be on equal footing than it is if one person uses



Fig. 5: A teacher shows a student how to perform the FIRM gesture correctly



Fig. 6: A teacher shows that it is time for GYMNASTICS using gestures and a pictogram

speech while the other points to cards or presses buttons. Unlike spoken language, where we cannot help a child to pronounce correctly by shaping their mouths and lips, we can assist children to perform gestures correctly by carefully guiding their hands.

People with motoric limitations find it more difficult to use gestures. But even then, gestures can be used successfully, as Hüning-Meier (2008) shows. Tactile forms of gesturing are suitable for people with visual impairment or blindness; these stem from deafblind pedagogy (see Wiese&Rascher-Wolfring, 2010). But for gestures to be used successfully in AAC, the whole environment must be tailored to gestures or must learn them together with the child.

An important principle in AAC is multimodality. It is not about choosing the one form of communication over the other. The best results are attained using individually coordinated, sensibly combined methods that use different channels of perception. A combination of gestures and visual aids such as pictograms is recommended – whether separate cards, placards or electronic devices.



Fig. 6: A student relates: on the weekend I enjoyed the SUN

Reference objects are also suitable for children with visual impairment and children who prefer the tactile modality (see Camenisch & Hunsperger, 2014).

Learning and teaching gestures

A child will learn gestures in everyday life; the more frequently it comes into contact with them, the quicker and more easily it will learn. At the beginning it is advisable only to use gestures to visualise those words which are important to the child and which it enjoys. Depending on resources and the child's motivation, the number of gestures can then be increased. Again,

when choosing these new gestures, it is important to follow the child's inclinations. A gesture representing its favourite toy will interest the child much more than ones representing daily care routines. If the child discovers that actively performing the gesture means it receives the toy immediately, that will affect its motivation for using gestures very positively. To ensure that a child experiences this kind of self-engendered success using gestures as often as possible, it is essential to employ 'little words' early on which the child can use in different situations to achieve a big, desired effect. These words include things like AGAIN, MORE, NO and FINISHED.

Furthermore, gestures can be taught and learned in structured group settings such as daily greeting and farewell rituals, when looking at a picture book, signing children's songs and role-playing. Because all children enjoy talking using their hands, this playful way of teaching gestures is especially suitable for inclusive education (see also Bärtsch-Senn&Carigiet Fitzgerald, 2013).



Fig. 7: A class in the morning ritual

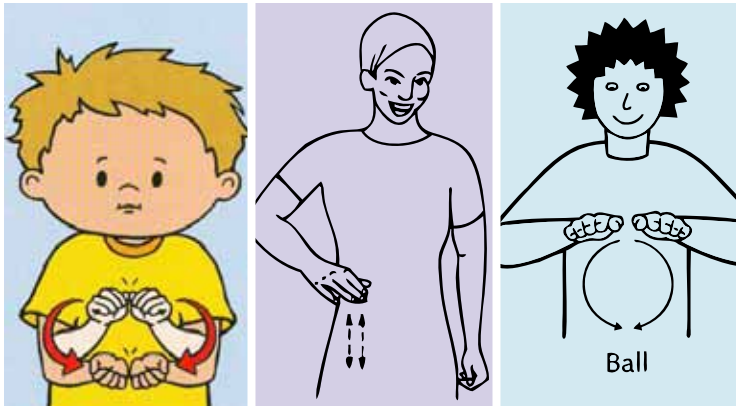


Fig. 8: The BALL gesture in three collections: DSGS illustrated by fingershop.ch, Wenn mir die Worte fehlen, Mit den Händen sprechen (left to right).

Towards a new Swiss collection of gestures

The Verein Förderung der Gebärdensprache bei Kindern (Association for the Promotion of Sign Language Among Children) offers materials for working with Swiss-German sign language through the fingershop.ch publishing house. There are however various collections of gestures in Switzerland which can be used for augmentative and alternative communication. The most widespread is the collection by Anita Portmann called *Wenn mir die Worte fehlen* (When I'm lost for words) which was specially designed for communicating with people with mental disabilities. But the Tanne gestures called *Mit den Händen sprechen* (Talking with your hands), which were specially developed for deafblind people, and those of Swiss-German Sign Language (*Deutschschweizer Gebärdensprache*, DSGS) are also used a lot. In practice what often happens is that in any given institution, the disabled people and their carers will have been trained in different collections.

Some of the gestures are very different, and this can

give rise to situations in which people do not understand or misunderstand each other. To resolve these problems, Tanne and Anita Portmann are currently working on a project to establish a common collection of gestures that will replace previous collections (see Portmann, Camenisch&Camus, 2016). It will offer a first and basic vocabulary that is compatible with DSGS. Yet the collection will suggest just one gesture for each concept, making it more accessible for users with learning difficulties. Furthermore it will be sufficiently tactile for deafblind communication partners and as easy to perform as possible for users with motoric and/or cognitive limitations.

Overall this coming new Swiss collection of gestures will help to reduce communication-barriers and will make it easier to produce and exchange materials used by people with disabilities and their teachers and carers for learning gestures.

Bibliography

- Bärtsch-Senn U., Carigiet Fitzgerald, A. (2013): *Hände hoch! Ein Gebärdenkoffer für Kinder*. Master's thesis submitted to the University of Applied Sciences of Special Needs Education in Zurich. Available in full at www.nebis.ch.
- Camenisch, A., Hunsperger, J. (2014): *Taktil kommunizieren über Bezugsobjekte*. In: *Schweizerische Zeitschrift für Heilpädagogik*, Volume 20, 11–12.
- Hüning-Meier, M. (2008): *Über den Einsatz von Gebärden bei körperbehinderten Menschen*. In: von Loeper, Isaac, Editor. *Handbuch der Unterstützten Kommunikation*. Karlsruhe: von Loeper: 02.015.001.
- Michel, A. (2015): *Materialien zur Kommunikation mit Gebärden*. In: von Loeper, Isaac, Editor. *Handbuch der Unterstützten Kommunikation*. Karlsruhe: von Loeper: 02.013.001.
- Nonn, K. (2014). *Gesucht wird eine Lokomotive, die den Spracherwerb zieht: das sozialpragmatische Spracherwerbsmodell von Michael Tomasello als theoretisches Bezugssystem für Unterstützte Kommunikation. uk & forschung_3*. Karlsruhe: von Loeper Literaturverlag.
- Portmann, A., Camenisch, A., Camus, M.: *Das Projekt der 'Tanne-Portmann-Gebärden'*. In: *Schweizerische Zeitschrift für Heilpädagogik*, Volume 22, 7–8.
- Papoušek, M. (2001). *Vom ersten Schrei zum ersten Wort*. Berne: Verlag Hans Huber
- Tomasello, M. (2014). *Die Ursprünge der menschlichen Kommunikation*. (3rd edition). Frankfurt am Main: Suhrkamp Verlag.
- Wiese, J., Rascher-Wolfring, M, 2010: *Taktiler Gebärden*. In: von Loeper, Isaac, Editor. *Handbuch der Unterstützten Kommunikation*. Karlsruhe: von Loeper: 02.030.001.

Sign language collections and materials

- Portmann, Anita (2012): *Wenn mir die Worte fehlen*. The 'Wenn mir die Worte fehlen' Association.
- Swiss Deaf Federation: Online sign language lexicon of the Swiss Deaf Federation SGB-FSS: <http://signsuisse.sgb-fss.ch/#>
- Tanne, Swiss Foundation for the Deafblind (2007): *Mit den Händen sprechen*.
- Ubi levitas (2014): *Erste Gebärden. Frühling*. Allschwil: Verlag fingershop.ch www.ariadne.de/von-loeper-literaturverlag/ www.fingershop.ch

Welcome to DbI Conference 2017 in Denmark

We are pleased to be holding the 9th DbI European Conference on Deafblindness in Aalborg, Denmark.

The title of the conference is *Touch of Closeness – maintaining social connectedness*. The central theme of the conference is social connectedness. Social connectedness is about how people come together and interact. We hope you will take this opportunity as professionals, individuals with deafblindness and their families to come together and meet at the conference in Aalborg in September 2017.

The scientific program includes plenary sessions, workshops, poster presentations, research symposium, network meetings and a possibility of visiting the Center for Deafblindness and Hearing loss in Aalborg.

Please visit the website for all information about the conference: www.dbi2017denmark.com

First plenary speakers



Closeness and ageing

Joris Slaets
Professor of Geriatric Medicine
University Medical Centre Groningen,
the Netherlands



Touch and the Body: tactile awareness and the science of interpersonal touch

Alberto Gallace
University Researcher, Department of
Psychology,
University of Milano-Bicocca, Milano, Italy

Find more details about the programme and the speakers at the conference website.

SUBMISSION OF ABSTRACTS FOR WORKSHOP AND POSTER

The Scientific Committee invites delegates to send proposals for a workshop or poster presentation held in conjunction with the main conference. The purpose of a workshop or poster presentation is to provide an opportunity for participants from the practical as well as the research field to present and discuss ideas on topics relevant to deafblindness. We are looking for ideas that are inspirational, stimulating, innovative and provocative.

Submissions have closed.

For more information please take a look at www.dbi2017denmark.com

SUBMISSION OF ABSTRACTS FOR RESEARCH SYMPOSIUM

We invite researchers and research-students to participate and contribute with presentations at the research symposium on September 7, 2017.

The symposium will address both acquired and congenital deafblindness and will each consist of a 15 minute presentation followed by 5 minute short talks on specific topics.

Deadline is April 7, 2017.

You will find information about the six topics, submission and deadlines at www.dbi2017denmark.com

EARLY BIRD REGISTRATION NOW

Why not take advantage of the lower conference price up until February 25, 2017?

Registration for the conference is now open. Please visit the conference website: www.dbi2017denmark.com where you will find all details about the conference prices etc.

PRE-CONFERENCES

We warmly welcome independently organized pre-conferences to be held within the conference venue in Aalborg ahead of the main conference taking place on September 5–8, 2017. One day pre-conferences to take place on September 3 or 4, and two day pre-conferences to take place on September 3–4, 2017.

In order to book meeting facilities and meals for a pre-conference please contact conference coordinator Helle Buelund Selling, helle.buelund@rn.dk, at the latest February 25, 2017.

You will find updated information about the pre-conferences at www.dbi2017denmark.com. The following have already signed up: Deafblind International Youth Network (DbIYN), Nordic Day by NVC, DbI Usher Network, All about CHARGE by DbI CHARGE Network. More to come?

NETWORK MEETINGS

We invite all DbI Networks to take the opportunity to arrange network activities at the conference venue in Aalborg on September 7, 2017. The Scientific Committee has specifically allocated this afternoon at 15:30–17:00 to network activities and which is a great occasion for DbI Networks to share knowledge and expand their work and activities.

In order to book meeting facilities for networks activities please contact conference secretary Jytte Olsen, jytte.olsen@rn.dk, at the latest May 31, 2017.



IMPORTANT DATES

Submission of abstract for poster and workshop sessions: **deadline January 10, 2017**

Early Bird registration: **deadline February 25, 2017**

Booking meeting facilities for a pre-conference: **deadline February 25, 2017**

Submission of abstracts for research symposium: **deadline April 7, 2017**

Booking facilities for DbI network meetings: **deadline May 31, 2017**

Registration: **deadline May 31, 2017**

Pre-conferences take place: **September 3–4, 2017**

9th DbI European conference takes place: **September 5–8, 2017**



Deafblind International (DbI), the Acquired Deafblindness Network (ADbN), together with the organizers in Denmark – the Centre for Deafblindness and Hearing Loss (CDH), the Centre for Deaf (CFD), The National Board of Social Services (Social Styrelsen) welcome participants for the 9th DbI European Conference.

www.dbi2017denmark.com



DEAFBLIND INTERNATIONAL

DbI on CHARGE Syndrome

September 4th, 2017 Aalborg, Denmark

All about CHARGE – 2nd preconference of DbI CHARGE Network

NO.	TIME	PROGRAM
	08:00–08:30	Coming together
Something about the body...		
1	08:30–09:00	Fun Chi with Sharon Grassick
2	09:00–09:30	What is that Fun Chi? (speaker: Sharon Grassick/Australia)
3	09:30–10:15	Posture and movement (speaker: David Brown/USA)
4	10:15–10:45	Morning coffee break: Time for sharing
Something about communication...		
5	10:45–11:30	The role of vision and touch in joint attention (speaker: Marga Leefkens-van den Broek/Netherlands)



NO.	TIME	PROGRAM
7	12:15–13:30	Time for lunch and sharing of ideas
Something about identity...		
8	13:30–14:15	Socialization dyads-of older and younger students (speaker: Susan Bruce/USA)
9	14:15–15:00	Self identity of young adults (speaker: Lynn Skei/Norway)
10	15:00–15:30	Afternoon coffee break
11	15:30–16:15	Beginning of a lifeline (speaker: Susan Bashinski/USA)
12	16:00–16:45	Space for questions, discussion and wishes from DbI CHARGE Network

Usher Network Pre-conference

Aalborg Congress & Culture Center, Aalborg, Denmark

3rd and 4th September, 2017

CALLS FOR EXPRESSIONS OF INTEREST

We are very proud to announce there will be an Usher Network Pre-conference to be held in Denmark on Sunday 3rd and Monday 4th September 2017.

“BUILDING BLOCKS OF SOCIAL CONNECTIVITY”

This will provide a fantastic opportunity for people to share ideas and network within the sphere of the Usher community.

The theme of our network pre conference is “Building Blocks of Social Connectivity” (run in conjunction with the DbI European conference; ‘Touch of Closeness – Maintaining social connectedness’).

We will focus on several speakers from the genetic and psychological disciplines as well as personal stories to highlight what it is like living with Usher. If you would like to give a presentation, or are interested in facilitating one of the café style networking slots, please contact Emma Boswell. Or you can just come and join us for the Usher Network Pre-conference, for more info: ushernetwork@gmail.com

Full details can be found on the network section of the DbI international website or please see our Usher Network webpage link: <http://usher.deafblindinternational.org/>

We would like to increase our membership community, to join the network please contact us at the same email address above.

Information about fees, registration, speakers and exact time will be announced on www.dbi2017denmark.com in the beginning of 2017.

We are looking forward to seeing you.





Announcement – Deafblind International Youth Network (DbIYN) Activity 2017



- Two days of activities in the Danish city of Aalborg
- Network workshops and evening entertainment
- Two nights hotel accommodation in Aalborg
- Presentations on services for Deafblind Youth

September 3rd – September 4th

Dates are prior to the 9th DbI European conference in Aalborg

For further information on this exciting network activity and booking details please contact the network coordinator simon.allison@sense.org.uk

Deafblind International is heading down under!



Queensland, Australia
12-16 August 2019

Hosted by Able Australia, the 17th Deafblind International World Conference will be held on the Gold Coast, Australia on **12-16 August 2019**.

Mark this date in your diary and watch this space for more information.

For information, email us at dbi2019@ableaustralia.org.au or visit www.ableaustralia.org.au/dbi2019



The DbI Communication Network, together with the Department of Special Needs Education and Youth Care, Groningen University¹, The Netherlands, hosted the conference titled: **Communication in the context of congenital deafblindness, November 15–17, 2016.** The conference celebrated the successful ten years of the International Masters of Education in Communication and Congenital Deafblindness Program at the University. Dr. Marleen Janssen, Director of the Masters Program, chaired this most successful event.

Some 133 individuals representing 18 countries² took part in this event, which included nine of those who were Keynote speakers, Plenary presenters or Responders, and 24 individuals who singularly or jointly delivered 20 workshops over the three action packed days.

The conference opened with welcome speeches from such University of Groningen Dignitaries as Professor Dr. C. Aarts (Dean Faculty of Behavioural Sciences) and Professor Dr. A. Minnaert (Department Special Needs Education and Youth Care) who both indicated their pleasure to welcome so many international professionals attending this event. They also extended praise to the DbI Communication Network organizers, who over the past ten years, developed and delivered the course of studies, (together with Director Dr. Janssen) that produced 64 Masters Thesis over the past ten years.

The Communication Network members in attendance included Ton Visser (Netherlands), Inger Rodbroe (Denmark), Anne Nafstad (Norway), Jacques Souriau

(France), Marlene Daelman (Belgium) and Marleen Janssen (Netherlands).

Keynote and Plenaries

The conference keynote presentation titled **Theory and Practice** was delivered on the opening morning (November 15) by Anne Nafstad (Norway) and Marlene Daelman (Belgium), both long standing member of the DbI Communication Network. They described how concepts, methods and intervention designs evolved since the DbI Communication started to work 27 years ago. The Keynote response was presented by Professor Wied Ruijsenaars, Professor of Orthopedagogy from the University of Groningen.

The first plenary (I) was presented on the opening morning by Professor Ivana Markova, Psychologist, Professor Emeritus, from the University of Stirling, Scotland³. She introduced the audience to the state of the arts of the Dialogical Theory which promotes the idea that thinking and communicating are essentially dialogical. She illustrated her presentation with examples of

intervention drawn from the field of congenital deafblindness.

Plenary II, titled **Language Development: Valuable Observations**, was delivered on Day Two, November 16, by Professor Dr. Stephen von Tetzchner⁴, Professor of Developmental Psychology, University of Oslo, Norway⁵. He presented a wide and critical view of the methods, designs and dynamics that can be found in the various types of interventions addressing people with disabilities involving communication challenges.

Dr. Marleen Janssen presented the response to Dr. von Tetzchners plenary.

Plenaries III and IV were presented on the final day of the conference, November 17. Plenary III, titled: **Embodiment, Agency and Intersubjectivity**, was presented by Dr. Shaun Gallagher, University of Memphis, USA.⁶ Dr. Gallagher is an Irish-American philosopher who works on embodied cognition, social cognition, agency and the philosophy of psychopathology. Since 2011 he has held the

¹ www.rug.nl/.../university-of-groningen-department-of-special-need.

² Counties represented and number of participants per country: Belgium (5); Brazil (3); Canada (3); Croatia (3); Czech Republic (1); Denmark (7); Finland (1); France (3); Germany (2); Ghana (1); Malawi (1); Netherlands (52); Norway (20); Russia (4); Sweden (21); Taiwan (1); UK (3) USA (2)

³ rms.stir.ac.uk/converis-stirling/person/10715

⁴ https://de.wikipedia.org/wiki/Stephen_von_Tetzchner

⁵ <http://www.uio.no/english/>

⁶ www.memphis.edu/philosophy/people/bios/shaun-gallagher.php

Lillian and Morrie Moss Chair of Excellence in Philosophy at the University of Memphis. The response was given by Jacques Souriau, one of the members of the DbI Communication Network, along with Kirsten Schou, a Master student. Together, they illustrated how the notion of embodiment is used for understanding and reacting to the expressions of congenitally deafblind people.

The final plenary, Plenary IV, titled: **Dialogue and the Birth of the Individual Mind (with an example of Congenital Deafblindness)** was delivered by Per Linell, Senior Professor in the Professor Per Department of Education, Communication and Learning at Göteborg University, Sweden⁷. Dr. Linell is also Emeritus Professor of Language and Culture at Linköping University, Sweden.

Workshops Sessions

Each afternoon featured concurrent workshop sessions. With four exceptions (workshops from Canada, Brazil, Denmark and the Netherlands), 16 of the 20

workshop presentations were a selection of the Master Thesis from the ten years of the program. Interestingly, the distribution of the Master Presentations by country were: Netherlands (6), Norway (5), UK (2), Canada (1), Denmark (1) and France (1).

Other activities

After each morning plenary, time was made available to conference participants for a group discussion.

Conference participants were also divided into separate groups to allow for round table discussions about particular issues connected with congenital deafblindness. Each of the groups was chaired by one of the Communication Network members.

At the end of each of the first two days, poster and film sessions were set up for interested participants.

Launch of a National Centre of Expertise. A skype conference call was set up from the Bartimeus Deafblindness Centre announcing that the four centres of expertise in the Netherlands (Bartimeus⁸, Kentalis⁹, Royal Visio¹⁰ and Stichting

Kalorama¹¹) together were establishing a National Centre of Expertise in Deafblindness.

Plenary Feedback and Closing Speech

At the end of Day 3, Plenary speakers Markova, Gallagher and Linnell participated in a group discussion which was followed up by a closing presentation by Marleen Janssen. The DbI Network organizers were celebrated at the closing for their incredible work over the past ten years which culminated in this conference.

Closing Dinner Party

Participants were invited to a Dinner Buffet and Party with DJ in the evening following the conference. This event was sponsored by Kentalis. At this event, two of the long standing members of the DbI Communication Committee, Inger Rodbroe and Ton Visser, were honoured as they retired from this prestigious group.

Stan Munroe
DbI Information Officer



⁷ lincs.gu.se › University of Gothenburg

⁸ Bartimeus (www.bartimeus.nl) is a small corporate member of DbI.

⁹ Kentalis (www.kentalis.nl) is a large corporate member of DbI.

¹⁰ Royal Visio (www.visio.org) is a small corporate member of DbI.

¹¹ Kalorama (www.kalorama.nl) is a small corporate member of DbI.

Conferences



African Federation of the Deaf Blind (AFDB)

A Request for Partnership

Dear Prospective Partners:

During the past Executive meeting of the newly elected AFDB that took place in Johannesburg South Africa on the 21 November 2014, AFDB leaders defined its future activities.

As a new President of AFDB I am now faced with significant obstacles that the organization struggles with daily. Realistically, AFDB does not have the financial resources to have any permanent employees despite the fact it has an office registered in Malawi ready to take on projects. In addition, all the Executive Committee members are deafblind persons, demonstrating dual sensory impairment in various degrees of impairment. It is a fact that our members all possess limited communication ability and as well lack quality communication support, which together seriously limits our ability to acquire

good skills and knowledge. All of this affects the speed of growth and progress of AFDB, which is why AFDB remains an inexperienced federation.

The few of us who have high-quality communications abilities and/or support, struggle on daily basis to invest every effort to enhance our visibility and provide as much resource available to develop the African Federation of the Deafblind (AFDB). Considering all the obstacles mentioned, this task is extremely difficult for us. But we strongly believe that through our own will supported by good quality external advice and assistance, our objective is certainly attainable.

With these constraints in mind, AFDB is appealing to organizations to partner with us to help with our struggle to implement various projects to improve conditions for persons with deafblindness in our countries. We are looking for assistance in,

but not limited to, the following areas: Leadership/ Governance; Organizational systems; Personnel Management; Disability rights and inclusion advocacy skills; Research; Technical knowledge (accessible ICT, Accessibility Standards, etc.); Knowledge about Sustainable Development Goals (SDG) monitoring and reporting, etc.; advocacy skills on rights and inclusion of Women, Girls and Children with Disabilities.

We look forward to an indication of your support and a future partnership with us to help the AFDB membership realize our dream to become the true Voice for deafblind persons in Africa, with the consequence of achieving our fundamental human rights and creation of a better future for all of us.

Looking forward to hearing from you and thanking you in advance,

**Ezekiel Kumwenda,
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MY DISABILITY THOUGHT OF THE DAY:

I sometimes wish I was a deaf sighted person so that I would be more independent and able to drive without having to depend on other people for assistance all the time. I sometimes try to analyze why I am deafblind but the answer always remains a mystery that never will be solved. However, I always try to search for hope and positive support to help me find the confidence to enable me to be as independent as a DB person can and be able accomplish anything. I believe that there is hope that those of us who are deafblind will support each other and learn how to be independent as a deafblind community, where no one should ever be alone again. In this community, through supporting each other, believing in ourselves, we can accomplish anything.

Ezekiel Kumwenda

Australia



10th National Deafblind Conference

FREMANTLE 2016

"Celebrating Experiences Across the Lifespan"

Senses Australia hosted the 10th National Deafblind conference, on behalf of the Australian Deafblind Council on 16 and 17 November 2016 in Fremantle, Western Australia.

Senses Australia has a long history of involvement with people with sensory disability, originally providing services for people with a vision impairment over 120 years ago. It now continues that involvement with the provision of quality services for people who are deafblind, including advocacy and support services.

The scientific committee put together a very engaging program, with people who are deafblind sharing their experiences, service providers demonstrating innovative programs and researchers showcasing some of their work.



Shaun Nannup (Noongar man who conducted the Aboriginal welcome to the country) and Debbie Karasinski (Senses Australia CEO)



Key note speaker, Molly Watt, a 21 year old from Maidenhead Berkshire, England gave an inspirational address outlining her challenges and successes. Molly was born with Usher syndrome and uses technology and social media to advocate for the needs of people who are deafblind



Dr Walter Wittich



Heather Lawson, President of the Australian Deafblind Council 'listening' to a conference presentation

Australia continued



Our team of interpreters



Vanessa Vljakovic (deafblind and 2016 WA Young Person of the Year), Anne Burroughs (interpreter) and Melissa Evans (deafblind consultant, Senses Australia)

The conference included the Australian Deafblind Council AGM and finished with a gala dinner, which had a band comprised of young people with and without a disability, including a young man playing keyboard with deafblindness.

Feedback indicated that all deafblind delegates were able to fully access the conference through the careful planning of the organising committee meeting individual needs.

Thank you to everyone who participated.

For more information, contact Matthew Wittorff at Matthew.Wittorff@senses.org.au

Australia
continued

Usher Pre-conference

Fremantle, Western Australia, November, 2016

On Tuesday, the 15th of November, 2016 Senses Australia¹ and Deafblind International (DbI) Usher Syndrome Network² were proud to host the Usher pre-conference, as a preamble to the 10th National Deafblind Conference in Fremantle, Western Australia. There had not been an event of this nature since the 2007 DbI World Conference was held in Perth, Western Australia.

Facilitated by Karen Wickham from Senses Australia the following speakers presented at the event: Alana Roy is a Mental Health Social Worker and

Provisional Psychologist at Able Australia³ Deafblind services. She is currently doing a PhD with Melbourne University titled “Working with deafblind people to develop a good practice approach to consultations and research activities”. Alana is also doing her Diploma of Auslan⁴ and is passionate about counselling, mental health and wellbeing of people living with Deafblindness. Her presentation on “Mental health and the Wellbeing of people with Ushers” highlighted the value of group work with this population to facilitate inclusion, healthy relationships, communication and maintaining good mental health.

Dr John De Roach is the Chief Investigator for the Australian Inherited Retinal Disease Register and DNA Bank (AIRDR)⁵, situated at Sir Charles Gairdner Hospital⁶. He has been involved with the AIRDR since its inception in 2009. The AIRDR contains 5600 DNA samples and associated clinical information from families affected with an inherited retinal disease. Dr de Roach discussed the current status of research into the genetic causes of Usher syndrome in Australia. Many participants are now keen to register with the DNA bank and be eligible for trials in the future.

Dr. Constance Miles has worked with individuals who are deafblind across the United States and the Pacific. Her doctoral dissertation was a qualitative study of the experiences of individuals with Usher syndrome in the American vocational rehabilitation system. She has worked with the Boys Town Usher Syndrome Project⁷, the Helen Keller National Center⁸, as a VR counselor in Hawaii, and as a consultant for universities, schools, and governmental programs. Dr. Miles presented on her thesis “After the Diagnosis” and shared some of the insights gained from her research participants.

Finally an expert panel with representation from parents, children, siblings and people living with Usher’s Syndrome directed a group discussion about living with Usher’s, family and coping with life transitions. This was a wonderful forum to allow a holistic view of families living with Usher syndrome.

All speakers were very well received and generated much discussion during and after the pre-conference. It was a worthy prelude to the beginning of the National Deafblind conference and has helped to build and strengthen the National Usher community immensely.

For more information contact Karen Wickham at karen.wickham@senses.org.au



¹ Senses Australia (www.senses.org.au) is a large corporate member of DbI.

² www.usher.deafblindinternational.org

³ Able Australia (www.ableaustralia.org.au) is a large corporate member of DbI

⁴ www.auslan.org.au

⁵ www.irdregister.org.au

⁶ www.scgh.health.wa.gov.au

⁷ <https://www.boystownhospital.org>

⁸ <https://www.helenkeller.org/hknc>

Deafblind Youth Leadership Program

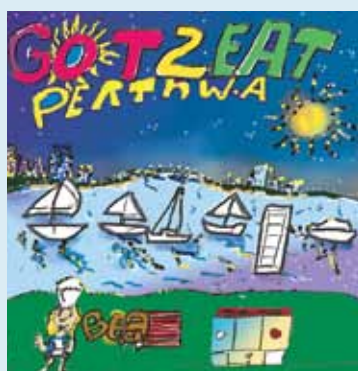
Australia
continued

The Senses Australia “Deafblind Youth Leadership Program” provided assistance to individuals who are deafblind aged between 15–26 years to develop their skills to enable them to undertake more significant leadership roles in their personal or professional lives. The objectives of the program were as follows:

- To develop leadership within youth who are deafblind
- To provide opportunities for youth who are deafblind to be included within mainstream community or educational activities
- To increase the social participation of youth who are deafblind
- To increase the awareness of deafblindness within the community

Five youths with deafblindness participated in the program. The project was based on individual goals and provided financial assistance to support these goals. Each participant initially attended a group session with a leadership consultant to gain a greater understanding of leadership and to develop a leadership plan. They were then supported by a deafblind consultant from Senses Australia to implement their plan.

The Deafblind Youth Leadership Program provided the opportunity for clients to actively identify and pursue goals that contributed to building their confidence, their inclusion, their skill base, their communication skills, their community and their leadership skills. Assessment



involved the individual (and some with their family) identifying areas for development and then setting SMART goals. Individuals then established a baseline of their satisfaction and performance in relation to each of their goals. Measures on both these domains were on a scale of 1 to 10. For satisfaction, 1 was “not satisfied at all” up to 10 being “extremely satisfied”. For performance, 1 was “not able to do at all” up to 10 being “able to do extremely well”. The deafblind youth and their family then re-evaluated their goals at the end of project.

Overall there were 7 goals. One participant’s goal was to research and identify a suitable device to support her in her educational pursuits. Partially as a result of this device and the support provided via

the program, she has now successfully completed her first semester at university. Another participant’s goal was to photograph the Deafblind UK Youth exchange group (Got2Act) and produce a thank you iPhoto book as a gift for the group. Once an appropriate device was identified and e-training scheduled, this participant built her skills and confidence. She attended and documented all the activities which was a significant accomplishment as previously she was not very social. In addition to documenting the Deafblind UK Youth exchange, photographs and YouTube clips have been shared throughout the world, contributing to raising awareness about deafblindness in the broader global community.

It is clear that the individuals achieved the leadership goals which they identified and worked upon. Participants and their families provided feedback that they observed increased levels of confidence in the deafblind youths and the program motivated them to follow up other opportunities. Life skills developed through the project have been applied in

INDIVIDUAL GOAL OUTCOMES:

Goal satisfaction	Range	Average
Initial assessment	1 – 6	2.5/10
Final assessment	8 – 10	9.7/10
Goal performance	Range	Average
Initial assessment	1 – 5	2.7/10
Final assessment	8 – 10	9.7/10

Australia continued

other situations such as the workplace and educational settings. One participant's employer has observed and reported that she has now been taking greater initiative in helping others in the workplace due to this increased confidence.

There have been a number of unexpected outcomes. These include:

- In order for one participant to achieve his goal of completing an Iron Man (rigorous training regime in each of the disciplines – swimming, running, cycling), he conducted a 'search for community volunteers' for training buddies in each of the disciplines. This search for volunteers led to the story being picked up by the Rural Community newspaper and television news and as a result an army of volunteers from the local community (gyms, marathon clubs,



cycling clubs etc.) provided significant support throughout and after the project. Encouraged by his success, the participant whose goal was to complete an Iron Man applied to and has been asked to participate in the 'Talent 4 Tokyo' program, which is the try-outs for the 2020 Australian Paralympic Team.

- As a result of pursuing her goal in photography, one participant subsequently applied for an ArtStart program. She prepared well for her interview and her confidence impressed the panel. She was offered a place in the program.
- On the strength of the relationship built with the Deafblind UK Youth that visited Perth – some participants are now planning an exchange visit to the UK, so new friends can return the support they were offered whilst in Perth and so WA Deafblind Youth can have the opportunity

to expand their friendship groups, travel and be ongoing contributing members to the World deafblind community.

This program highlighted the need to specifically support youths with disabilities, in particular those who are deafblind. Deafblind youths are keen to be more involved and this program has decreased some of the social isolation they had been experiencing. Ideally a forum (and funding) to enable deafblind youths to meet more often where they can support their peers would be very beneficial. Being able to access the ongoing support of Senses Australia's deafblind consultants was a significant contributor to ensuring participant dreams became reality.

Matthew Wittorff
Disability Professional
Services Manager
Senses Australia



Grupo Brasil hosts another successful Symposium

Held May 17–20, 2016 in Sao Paulo, Grupo Brasil¹ hosted the VI International Forum on deafblindness and multiple sensory disabilities and the II Ibero-Latin American Meeting in the field of deafblindness and multiple sensory disabilities. The overall theme of this event was the promotion of dialogues on health, education and rights within the specialized educational services to ensure the inclusion of the persons with deafblindness and multiple sensory disabilities.

Three hundred participants from different parts Brazil who work with people with deafblindness registered for the forum, with many presenting oral presentations or poster sessions about their research or experience in their various practices.

The forum also featured fifteen plenary sessions and video conferences focusing on the following: Charge Syndrome, Congenital Rubella Syndrome, Usher Syndrome, Tactile Communication, Outdoor activities, Intervention, Social Haptic Communication, Universal Design for Learning, Teacher Training, Research, Assessment, Public Policies,

Assistive Technology, Latin American Panel Discussion.

For the plenary sessions, the forum was privileged to welcome the following International guest speakers: Joe Gibson (Norway); Carolyn Monaco (Canada); Timothy Hartshorne (USA); Maria Bove (USA); Isabel Amaral (Portugal); Oriana Elisabeth Donoso Araya (Chile); Ricardo Zevallos (Peru); Marleen Janssen (The Netherlands) and Ximena Serpa (Colombia).

Unable to attend in person, the forum was similarly pleased to welcome, by video conference, the following speakers: Marta Lucia Tamayo (Colombia);

Stan Munroe (Canada); Jude Nicholas (Norway); Russ Palmer (UK); Liz Hodges (UK) and Paul Hart (UK).

This event was a partnership between Grupo Brasil and the University of São Paulo², with support of funding from Capes³, the Research Foundation Fapesp⁴ and Uninove University⁵ whose auditorium hosted this event.

For more information about this event, contact Vula Ikinomides (vula2004@hotmail.com)



¹ www.grupobrasil.org.br

² www5.usp.br

³ <https://www.capes.gov.br>

⁴ www.fapesp.br/en

⁵ www.uninove.br

Brazil
continued

Instituto Bruno Vianna's involvement in the Paralympic Games 2016



The Rio Paralympic Games 2016 in Rio Brazil gave a special opportunity for some individuals with sensory and multiple disabilities at the Instituto Bruno Vianna¹ from the city of Juiz de Fora, in the state of Minas Gerais, to observe and interact with some of the disabled athletes participating in the 2016 Rio Paralympic Games. It was such a coincidence that some of the athletes were training nearby at the Federal University of Juiz de Fora. The Institute organized for five individuals with disabilities, accompanied by two language and three sign language interpreters, to meet and interact with the para-athletes in training. One of the athletes they met at the training location was

Kevin Strybosch, a discus thrower from Canada.

Instituto Bruno also arranged for these clients (with sensory and multiple disabilities) to watch a Ladies Sitting Volleyball match between the Netherlands and Iran taking place on September 15th at the Paralympic site in Rio.

The aim of these special field trips and interactions was to foster special social inclusion opportunities for the Institute's clients. These visits served as special opportunities to demonstrate to the clients that disabled individuals like themselves can participate in public sporting activities using their personal abilities, representing a further example of social inclusion.

Witnessing the Paralympic Games by the Institute's clients furthermore served to demonstrate the appreciation of athletes with disabilities as true athletes, highlighting their role in the competition regardless of the type of their disability

Some of the feelings staff members and clients shared from these experiences were: inspiration, determination and focus. "I feel like both a professional and an ordinary citizen as part of this process of inclusion and equality for all. I feel good about being on this path" said Maria do Carmo², Coordinator and educator at the Instituto Bruno Vianna. These Games make more visible the abilities each one has despite their disability.

¹ Instituto Bruno Vianna is a member of Grupo Brasil of Support to the Deafblind and Multiple Sensory Disabled (www.grupobrasil.org.br).

² Article originally written by Mario do Carmo, with editorial assistance from the DbI editor

Zoom In & Redefine

Canada

We are excited about **Zoom In & Redefine** – a new initiative between DeafBlind Ontario Services¹, CNIB Deafblind Services² and the Canadian Helen Keller Centre (CHKC)³. This partnership is aimed at: identifying the unique needs, building awareness; providing training; and advocacy of seniors with dual sensory loss. The partners are interested in redefining how society views seniors with both hearing and vision loss and challenging the perception that nothing can be done. Through this partnership, a service model will be created for seniors with dual sensory loss taking a person-centred, holistic approach to enhance all of the dimensions of one's well-being to help provide supports that address the specialized needs of this population of seniors and their families or caregivers.

Thanks to a grant provided by the Ontario Trillium Foundation⁴ for one year, we will be propelling this initiative forward with the help of a project coordinator.

According to the 2014–15 Canadian Institute for Health Information (CIHI)⁵ data for Ontario long term care and home care, of the 15.6 % of seniors who are 65 years of age and over, 6.5 % are in long

term care homes and 11.8 % are in home care settings. In both long term care and home care combined, 22 % are experiencing minimum to moderate hearing and vision loss combined and 2 % are experiencing severe hearing and vision loss combined. (This does not include those who have not come in contact with health services.)

We know from our research that with unmanaged hearing and vision loss, seniors can become withdrawn and socially isolated, which can lead to a breakdown in their support networks. This situation can subsequently place seniors at a risk of losing their independence and the ability to communicate, ultimately leading to mental health issues, such as depression. If not managed, seniors experiencing dual sensory loss are also at a greater risk of slips and falls, that can be prevented with proper orientation and mobility practices. Finally, maintaining health, safety and communication can all ultimately improve a senior's overall wellbeing.

To boost awareness and create linkages, the working group has been seeking opportunities to present at conferences



that focus on: gerontology, aging; accessibility; vision loss; and, long-term care. Communicating information about this new initiative and the resources available are key to helping different audiences across health, social service and disability sectors better understand the implications of dual sensory loss on individuals as they age.

We have started offering training for staff working in long-term care homes and home care settings. The training equips professionals like personal care workers and practical nurses with additional tools to enhance their care for seniors with dual sensory loss.

The training aims to help uncover simple solutions that can improve a person's quality of life, including their ability to socialize with others, engage in activities and maintain independence. For example, training will: introduce basic concepts for orientation and mobility; help develop a better understanding of



¹ www.deafblindontario.com. DeafBlind Ontario Services is a large corporate member of DbI.

² <http://www.cnib.ca/en/ontario/Pages/default.aspx>

³ www.chk.org

⁴ www.otf.ca

⁵ <https://www.cihi.ca>

Canada continued

dual sensory loss; and, inform attendees about alternate forms of communication.

To further illustrate these implications, sessions will include case studies to help articulate real life situations and guide discussions on what it is like to care for someone with dual sensory loss, including identification of the changes and challenges that can follow.

According to a 2012 Canadians with Disabilities Survey⁶, of the 3.8 million Canadians living with disabilities, almost 3% aged 15 years and older experience vision loss, which increases to 13.9% for those aged 65 years and older. More than 3% of Canadians aged 15 years of age and older have hearing loss which sharply increases to 21.9% for those aged 65 years and over. In addition, within the population of people aged 65 years of age and over, there is a reported 46.1% prevalence of a co-occurring vision and hearing loss.

As we continue our progress on this partnership, we encourage you to stay up to date by checking us out on our website <http://www.zoominandredesign.com>, and visiting us on social media through Facebook <https://www.facebook.com/Zoom-In-Redesign-921901717922980/> and Twitter <https://twitter.com/zoominredesign>.

For more information contact Karen Madho (scgrc@deafblindontario.com)

⁶ www.statcan.gc.ca/cgi-bin/IPS/display?cat_num=89-654-x

Intervenor Services Human Resource Strategy (ISHRS)



What is the ISHRS?

The Intervenor Services Human Resource Strategy (ISHRS) is a multi-year initiative, in partnership with the Ontario Ministry of Community and Social Services¹ (MCSS), which is focused on professionalizing intervenor services, increasing the availability of highly skilled staff therefore improving the quality of intervenor services delivery to adults living with deafblindness in Ontario, Canada.

What is the organizational structure of the ISHRS?

The ISHRS Steering Committee is Co-Chaired by Rosa Carlucci (Ministry of Community and Social Services) and Roxanna Spruyt-Rocks (DeafBlind Ontario Services). The Steering Committee oversees the work of four Sub-Committees: Best Practices in Human Resources Sub-Committee; Behavioural Competencies Sub-Committee; Education and Training Sub-Committee; and the Marketing and Communications Sub-Committee. Committee members are comprised of representatives from the 21 agencies providing Intervenor Services across Ontario.

What are the objectives of the ISHRS?

The ISHRS aims to achieve the following objectives within Intervenor Services: enhanced retention of Intervenor Services; increased recruitment of intervenors; improved onboarding of highly qualified Intervenor Services; improved access for Intervenor Services to professional development and training opportunities; improved access to appropriate educational programs and certificates for people interested in training as Intervenor Services; and, stronger partnerships among key organizations including associations, colleges, agencies and ministries.

How will the ISHRS achieve these objectives?

The ISHRS will achieve these deliverables through the following activities: implementation of behavioural competencies for Intervenor Services; determination of technical competencies for intervenors; development of a best practices toolkit for Human Resource professionals; and application of a marketing and communications strategy for Intervenor Services.

¹ www.mcscs.gov.on.ca/en/mcscs

How were consumers engaged in developing the competencies?

The competencies were developed based on feedback from focus groups with consumers and families, as well as interviews, surveys, and focus groups with Intervenors, supervisors and managers across the 21 agencies that receive Intenor Services funding from MCSS.

On June 1, 2016, the ISHRS attended JuneFest² to spread awareness about the ISHRS, and to collect information from consumers and families on the skills and knowledge required for an ideal Intenor. JuneFest is an annual awareness event held in Toronto for deafblindness. The ISHRS is committed to ongoing liaison and consultation with all stakeholders of the ISHRS.

What are the most recent achievements of the ISHRS?

On May 26 and 27, 2016, the ISHRS hosted an event: *Piecing the Puzzle Together*. The purpose of the event was to showcase the new behavioural competencies for Intenor Services for the roles of intervenors, supervisors and managers, to begin the process of collecting information from intervenors concerning their technical competencies or skills, and from Supervisors and Managers regarding human resource processes and performance management tools. The ISHRS presented a total of 15 behavioural competencies for Intenor Services. At the event, Hay Group, a professional consulting firm that was contracted to develop the behavioural competencies, in consultation with the Intenor Services sector, delivered a training session to 18 Trainers across the 21 agencies that receive funding from MCSS to deliver Intenor Services.

In the fall of 2016, a second workshop for trainers, “Coaching for Behavioural Competencies Workshop,” is scheduled for designated trainers to support them in coaching and developing employees.

The Best Practices in Human Resources Sub-Committee has been collecting tools from human resource departments and senior management across all 21 agencies. These tools will help inform the best practices HR toolkit. The committee is interested in learning best practices currently in use across the Intenor Services sector in specific areas of: recruitment, retention, recognition, onboarding and succession planning. This comprehensive toolkit will be complete by March 2017. These tools will be instrumental in supporting the full implementation of behavioural competencies across the sector.

Training on behavioural-based interviewing techniques will also be offered in winter 2016/17.

Next on the horizon... is the full implementation of all behavioural competencies within agencies across the sector between January and March 2017.

To keep up-to-date on the strategy, sign up for our e-newsletter on the website or via pcishr@deafblindontario.com.

Website: www.intenor-services.com

Facebook: www.facebook.com/IntenorServices

Twitter: <https://twitter.com/IntenorSrvcs>

France

The French National Association of Deafblind Persons (Association Nationale pour les Personnes SourdAveugle or ANPSA) recently released their new logo, which includes the acronym and a visual representation of deafblindness including a slogan meaning: “Let’s see and hear deafblindness”.



The visual representation of deafblindness consists of two pictograms – the shaded eye (representing blindness) nested in the crossed ear (representing deafness) behind the capital A.



“*The French National Association of Deafblind Persons (Association Nationale pour les Personnes SourdAveugle or ANPSA) recently released their new logo...*”

² www.junefest.ca

Germany

International congress: deafblind professionals expand their horizons



The musical kickoff of the congress “deafblind pedagogics in dialogue” featured the school band “No Guggies” from Heiligenbronn. The sign language interpreters Sabine Wanner (left) and Anke Hagemann were taken by the rhythm of the music.

In Schramberg-Heiligenbronn (Baden-Württemberg) from June 24th till June 25th, 2016, over 280 participants from throughout Germany and seven other countries participated in a congress titled: Dialogue about Deafblind Education. The objectives of the conference were to focus on numerous issues of importance in support of individuals with deafblindness, especially those with congenital deafblindness. Particular issues of focus included medical, pedagogical, psychological and communication aspects.

Professionals from the field of deafblindness, persons with deafblindness, their family members, and others including medical personnel and students, assembled at the Stiftung St. Franziskus¹ (Heiligenbronn) for two days to hear lectures from internationally renowned professionals. The Center of Expertise for Deafblindness in Heiligenbronn works together

with three other German institutions in a new training-project funded by the EU and also linked with organizations for deafblindness from the Netherlands, Switzerland and Austria.

Hubert Bernhard, Chairman of Stiftung St. Franziskus (Heiligenbronn) and the enthusiastic celebrated school band ‘No Guggies’ (Not Looking!) from the School for the Visually Impaired opened the program of the congress, welcoming the many, bridge-builders² among the participants. Mr. Bernhard said that the school band – performing the song ‘Astronaut’² – is the best proof of how to bare one’s heart, overcome constraints and establish connections. He spoke briefly about the location of the facility being a former convent, and described the activities of the foundation now 25 years in existence.

Gerd Weimer, Commissioner for the Disabled from Baden-Württemberg, thanked the

organizers for organizing this first-class congress to help the many partners in the field of deafblindness to become more aware of the issues facing these individuals. The commissioner expressed criticism about the draft new German Federal Government legislation concerning people with disabilities. “Having inclusion without funding is a non-starter”. Mr. Weimer suggested. Reiner Delgado from the German Association of the Visually Impaired and Blind also was critical of the draft legislation. For example, he said “that while the legislation introduced an appropriate ‘sign’ for persons with deafblindness, they were referred to in the legislation as individuals extraordinary visually and hearing impaired”.

During the congress everyone agreed to accept deafblindness as a disability *sui generis*³ (a Latin phrase, meaning “of its own kind; in a class by itself; unique”) and requiring specialized support. Ricard López from Barcelona, the Chairman of the EdbN (European Deafblind Network)⁴, supported very strongly the 2004 proposal of the European Union that people with deafblindness have a unique disability⁵. During his short welcoming speech, Ricard presented the initiative for a European Monitoring Centre for Deafblindness.

¹ <http://www.stiftung-st-franziskus.de/>

² www.azlyrics.com/lyrics/simpleplan/astronaut.html
Lyrics to “Astronaut” song by SIMPLE PLAN:
Can anybody hear me? Or am I talking to myself?
www.youtube.com/watch?v=exG595LaWxc

³ https://en.wikipedia.org/wiki/Sui_generis

⁴ EdbN is a DbI Network (<http://edbn.deafblindinternational.org>)

⁵ www.deafblindinternational.org/textonly/network_edbn.html

During the two day congress, twelve lecturers from the deafblindness professional field presented various lectures about their expertise relevant to the current situation of deafblindness understanding and services. Their presentations covered various topics including the various causes of the disability and suggestions for improved services for persons with deafblindness. Professor Dr. Markus Lang from the University of Education, Heidelberg⁶ explained about a recent research study conducted in ten Federal States of Germany which found that 95 % of the children with sensory disabilities also had additional disabilities. His report also stated that the many professionals working in facilities outside of those specializing in deafblindness are not aware of the kinds of support these disabled individuals require.

Roland Flaig, Head of the Care for Persons

with Disabilities in the St. Franziskus Foundation and Dr. Andrea Wanka⁷, Commissioner for the Deafblind in the Foundation (Leader responsible for adults and children with deafblindness), together made a presentation about the development of the training program for professionals in the context of the current EU project PropäK. Other presentations included discussions about the beginnings of communication; communication between individuals with deafblindness; the growing successful uses of cochlear implants, etc. Claudia Junghans, mother of a deafblind child with CHARGE syndrome, made an impressive presentation about the development of her son through the involvement of family members, various professionals and schools.

Inger Rodbroe from Denmark and Jacques Souriau from France, two co-

authors of the international standard work for deafblind pedagogics, lectured in Heiligenbronn. Rodbroe and Souriau explained that language is co-created between the person with deafblindness and their communication partner.

At the end of the second day of the congress, Dr. Michael Wollek, Chairman of the Foundation, summed up that the informative presentations has considerably expanded the level of knowledge and understanding of deafblindness among the participants. He also suggested there is much more to learn and understand about this field 'beyond the horizon'. He thanked the organizers, all the presenters and especially the persons with deafblindness and their interpreters for their attendance.

Written originally in German by Ewald Graf; translated by Nadja Urschel with numerous edits



In the first row from the right: Ricard Lopez (European Deafblind Network), Reiner Delgado (German Association of the Visual Impaired and Blind), Dr. Andrea Wanka (Commissioner for Deafblind in the Foundation), Claudia Junghans (German Self-Support Group CHARGE Syndrome), Dr. Johannes Fellingner (Linz), Professor Dr. Peter Martin (Kehl-Kork), Roland Flaig (Head of the Care for Persons with Disabilities in the Foundation).

Photos: Stiftung St. Franziskus

⁶ www.uni-heidelberg.de/index_e.html

⁷ Dr. Wanka is the coordinator for the DbI CHARGE Network (<http://chargenetwork.deafblindinternational.org>)

Ireland

Dr Jan van Dijk brings inspiration to Deafblind Ireland

On September 21–22, 2016 Deafblind Ireland and Child Vision had the great pleasure of hosting a visit from the eminent Psychologist and Deafblind Specialist Dr Jan van Dijk¹ to Dublin. His visit was short but eventful. On Thursday, Dr Jan did some consultations with people who are deafblind and brought great hope, encouragement and comfort to them and their families. On Friday, he gave a presentation to a large gathering of professionals and family members in the newly refurbished Conference Centre at Child Vision. As always, Dr Jan's talk was stimulating, enlightening, and occasionally provocative.

Joan Curran
Educational
Psychologist,
Deafblind
Ireland
(www.deafblindireland.ie)

The topic of this year's talk was 'Mental Health and Deafblindness.' Dr Jan rightly remarked that this topic would require much more time than the two hours available, but he managed to cram in a wealth of knowledge and insight. Speaking first about people who have an intellectual disability, he told us that in this population there is a serious failure to diagnose deafblindness. In his view, to claim that one 'cannot assess' people with severe and profound disabilities is not a tenable position to take, and that time, patience and knowledge can indeed lead to a satisfactory diagnosis, even with individuals who at first appear inaccessible to

intervention. In turn, having a correct diagnosis should lead to a better understanding of the person's needs, and proper accommodation made for activities of daily living, for mobility and social interaction.

For people with intellectual disabilities as for those who are intellectually able, appropriate stimulation and interaction is the clue to a healthy life. Even for those with no formal language, it is possible to connect emotionally through singing, gentle touch and acknowledgement of the person's feelings. Dr Jan illustrated this through video clips of his interactions with deafblind people with profound intellectual and sensory impairments.

Dr Jan also spoke about intellectually able adults with Usher syndrome, which involves profound sensori-neural deafness and a decrease of peripheral vision before puberty. He reported that, in spite of the extremely challenging situation they find themselves in, people he has worked with in the Netherlands have shown remarkable ego strength and resilience in meeting the challenges of their lives.

Based on the positive outcome found in his country, Dr Jan recommends the following measures to support the mental health of people with Usher Syndrome. They include:

- Trust that the person with Usher Syndrome has the strength to cope with the problems s/he encounters in daily life.
- Appoint a coach/family member who is always available.
- Organise a helpdesk for medical information.
- Encourage active membership of the deafblind community.
- Give information about the impact of the syndrome to family members, friends and employers.
- Assess the possibilities of low vision and hearing aids.
- Organise the participation in mobility courses and self-help skills.

There was much for us in Ireland to ponder about from Dr Jan's talk, and he could have continued talking to us all day. Unfortunately, it was soon time for him to be whisked away to Belfast, where another eager audience awaited him.

We look forward eagerly to his return.



Anne Marie Costelloe (Child Vision), Deirdre Leech (Anne Sullivan Centre), Dr Jan van Dijk, and Karen Coleman (Deafblind Ireland), with book

¹ www.drjanvandijk.org

Striving to make people who are Deafblind visible in Malawi

Malawi has over two million people living with disabilities, according to the 2008 national report released by the disability umbrella body, Fedoma¹. Of this total, about 25,600 were reported with sensory impairment, with either deafness or blindness. Individuals with deafblindness constituted about 3,150. Obviously one can see that the disability issue in Malawi is acute. Peter Ntoya is just one of those deafblind children. He is 8 years old and since his birth has never been 20 meters from his or his mother's house. VIHEMA Deafblind Malawi² recently discovered this boy through a tip and we have been following his situation closely. Just two weeks following his identification we await his acceptance into the Chisombezi Deafblind Centre³, the only facility that provides services to Deafblind children and youth in Malawi.

Martha Momba, VIHEMA Programs Coordinator
(vihema.deafblindmalawi@gmail.com)

PETER'S FAMILY STATUS

Peter's mother, Elube James, told us at VIHEMA the family's sad story. She said he was born normal but was infected with a bad case of Malaria when he was six months old. While he survived, he eventually showed signs of mental instability, followed by visual and hearing loss, compounded by incidences of epilepsy. His father Mr Ntoya, realizing he could no longer deal with this challenge, decided to divorce Peter's mother Elube, and opted for another woman who he felt could give him better children than Peter. At present, Peter's mother is renting a house in the poorest neighbourhood in the city of Blantyre, Malawi. To date VIHEMA has provided for Peter a Cerebral Palsy-style chair, a standing frame and some domestic assistance. We are striving to provide additional services to allow Peter to be ready to attend the Chisombezi school for the deafblind. We have included pictures of Peter and his mother in this case study so that you can appreciate the state of affairs that Peter is going through.



Peter Ntonya and mother



Peter Ntoya



Martha presenting CP Chair and frame to Peter

¹ FEDOMA - The Federation of Disability Organisations in Malawi (www.fedomamalawi.org)

² VIHEMA - The Vision Hearing Impairment Membership Association

³ chisombezideafblindcentre.weebly.com

Russia

Polygon – assistive technology space for deafblind

Modern technologies are playing an important role for individuals who are deafblind. However, many devices that those who are deafblind can use are not only extremely expensive but are also very difficult to use. Not to mention the fact that before one decides to buy a particular technical product, one should also be confident that it will be suitable for use. To solve this problem, the Deaf-blind Support Fund So-edinenie (Connection)¹ in cooperation with the Bauman State Technical University (BMSTU)² and the Centre «Enabling Technologies»³ have created just this past spring a specialized project called Polygon, an assistive technology space for individuals who are deafblind.

What is Polygon?

In Russia polygons are places for practicing or testing new products in specially adapted locations. In this case, the 'Polygon' for those who are deafblind is located in the Foundation's Resource Center, where these individuals regularly come to participate in the organization's activities. The main mission of the Polygon

is to provide the opportunity to test any modern technical aids for deafblind individuals and their families. Currently more than 70 types of devices are available for testing from the leading manufacturers from Russia, Europe, USA and Asia. These are products from companies as Istok-Audio⁴, Optelec Oticon⁵, Freedom Scientific⁶, Zooma⁷, etc.

Absolutely any person with deafblindness can apply to the Foundation to make an appointment for testing. They will be guided by a technical devices specialist and given an opportunity to scrutinize the products and try everything that seems interesting. In addition to individual visits to the Polygon, group workshops are provided where the Foundation's specialists and external experts talk about the application of specific devices.

In addition to visits from people who are deafblind, Polygon is visited by technical specialists, young technical device developers, teachers and psychologists from different regions in Russia. These visits significantly improve the disabled individual's awareness of modern technologies as well as providing them with practical skills to work with the most popular devices.

The Foundation's clients can learn and choose the proper device with the expert's suggestions as well as receive information about

where this device can be purchased and how to get sponsorship or charitable assistance for the acquisition of such devices.

Special attention is given to demonstrating innovative solutions to public and private customers who are interested in creating an accessible environment at their institutions.

Platform for innovation

Polygon objectives include not only providing technical devices for testing, but also contributing to the emergence of new technical solutions for those who are visually and hearing impaired. This area is attractive to technology researchers and developers, providing them the opportunity to test their devices or prototypes with an active group of people who are deafblind. As a result, the Foundation is implementing a unique Social Innovation Program titled 'Enabling Technologies 2.0', which is the main supplier of ready-to-test pilot programs.

Examples of developments

Since the official opening of Polygon in June of 2016, the space has already attracted more than one hundred people, nearly a third of them were deafblind. Twelve innovators made requests to test their new developments, of which three examples are given here.



¹ So.edinenie.org

² www.bmstu.ru/en

³ www.social-tech.ru/en/

⁴ www.istok-audio.com

www.us.optelec.com

⁵ www.oticon.com

⁶ www.freedomscientific.com

⁷ www.zoomax.co

**Russia
continued**

The first project is called *Tactile Hand* and is aimed at creating a tactile interface for the transfer and playback of data that can be interpreted by users who are blind or deafblind. The device, which looks like a leather bracelet, is worn on the wrist and transmits information using 6 vibrator motors, which encode Braille. Through the testing those who were deafblind noted that the perception of the information in this form requires some training and learning. Based on the recommendations and comments from the testing, the developers are preparing an updated version of the device for re-testing.

Another project is *Virtual Cane* developed by the well-known Dr. Amir Amedi from Israel. The testing that took place this past August attracted not only the sensory disabled persons (who wanted to independently verify the usability of a new electronic cane), but the attention of the leading Russian TV channels. This device uses 2 infrared sensors allowing people to find objects up to a 5 m distance. It is worth

mentioning that even after a brief acquaintance with the electronic cane almost all the persons with deafblindness noted that the cane was easy to use. This cane can also be used with a conventional white cane, requiring a special holder to be installed. Currently the Foundation is discussing with Amir Amedi the possible launching of this project in Russia.

The third innovation project is a tactile watch called FYT (Feel Your Time). This device is simple – one just needs to hold a finger on the circle tactile dial. A single vibration in the right sector indicates the number of hours; a double vibration indicated a number of minutes. These watches seemed to be comfortable for most of the Foundation’s clients who took part in the testing. The developer is preparing to release the first series of these devices for sale.

3D model

To provide the information about the devices represented in the Polygon, a 3D model of the actual room was created, where any device could be viewed with the additional

information, description, photos, videos, and even its 3D copy. All it requires is a modern web browser. Currently, there remains a lot of work to digitize all the devices, but the model itself is already available for everyone on the Foundation website (so-edinenie.org).

Denis Kuleshov, Head of the «Polygon» project, Head of the laboratory at Bauman University, Director on science and innovation at the Center «Enabling Technology» (email: polygon@so-edinenie.org)



ENABLING TECHNOLOGIES 2.0

This program supports projects aimed at the development or manufacturing of technological devices for individuals who are deafblind, scientists, researchers and other initiatives in the field of technology for individuals who are blind or deaf.

In order to attract new projects a special acceleration program has been developed. The projects within this program receive financial support, free training and advice, with an opportunity to have a personal academic adviser or mentor.

The results are that over 35 projects are being supported from 11 regions of Russia, with funding provided exceeding \$4,000,000.

Russia

From Exile to Stage: The story of Deafblind People Becoming Artists

Viktoria Avdeeva

As recent as 2014, people with deafblindness in Russia were unseen, forgotten and exiled due to various reasons, including accessibility and cultural issues, isolation and negative issues regarding state policy pertaining to disabled people. Since the recent development of the Deafblind Support Foundation 'Con-nection'¹ and the 'Touch-ables' project, much improvement has been made in the lives of deafblind people living in Moscow and throughout Russia, especially in regards to their cultural and social integration.

'Touch-ables' is the first play in Russia which tells the stories of 7 deafblind people, who together with hearing and seeing actors, present themselves on stage. It was produced in 2015

in collaboration with the Theatre of Nations² by the idea of its Artistic director Evgeniy Mironov³. Since April 2015 'Touch-ables' has been showcased 27 times in the leading theatres in Moscow and Saint-Petersburgh. It was nominated for two prestigious national theatre awards and became a well-known and successful brand in both theatre and charity. The project 'Touch-ables' – a play and art laboratory – has grown into a number of significant inclusive projects, significant not only in terms of theatre performances but for education and quality of life of deafblind people.

Inclusive theatre in Russia is just appearing on the scene and has developed very little interest among general audiences. To create an interest in this type of theatre requires interesting and highly artistic performances. To do this we brought together professors and directors from 3 different drama schools as well as actors with different types of disabilities (sensory, mental and physical) and abilities. The intent was to create a new theatre language and a system based on using the actors' abilities in an artistic way to achieve artistic and social goals. In October 2015, we launched a new project which was an Inclusive Theatre School in Moscow. Over a period of 3 months

at this Inclusive Theatre Laboratory, 3 groups from 3 drama schools representing different approaches worked with actors with different abilities to develop a new theatrical language. The results from this initiative were three classical productions performed at the Cultural Forum in December 2015: 'Marriage' by Gogol⁴, 'Seagull' by Chekhov⁵ and 'Carmen' by Merimee⁶. Each of the three 30-minute theatre sketches were evaluated by an international board of experts in drama and inclusive theatre and the production of 'Marriage' by the group from Russian State Institute of Theatre Arts took first place. The production was marked with the highest grades for 'Artistic value', 'Inclusion' and 'Innovation'.

In February 2016, we at Con-nection founded our own Inclusive Theatre School as an experimental cultural research platform. It has three dimensions: education, creativity and accessible fine arts.

The Educational laboratory is essentially a drama school for inclusive students and theatre professionals. Actors with different abilities can develop their artistic skills; theatre professionals can learn to be inclusive theatre specialists; inclusive theatre specialists can upgrade their skills in directing and acting. Inclusive actors



¹ So-edinenie.org

² www.theatreofnations.ru

³ http://www.imdb.com/

⁴ [https://en.wikipedia.org/wiki/Marriage_\(play\)](https://en.wikipedia.org/wiki/Marriage_(play))

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

⁶ [https://en.wikipedia.org/wiki/Carmen_\(novella\)](https://en.wikipedia.org/wiki/Carmen_(novella))

have two options: if they want to become professional actors and take part in productions, they can choose a professional program. If they are interested in developing their potential and improving communication skills, they only attend classes, making in-class performances.

In the creative laboratory different directors and actors experiment with new theatrical forms to create new plays and art projects. During the period January through May 2016 the three groups continued to work on their pieces. In May the full version of 'Marriage' was presented to the public with high reviews from theatre critics and the audience. The director Mikhail Feigin succeeded in finding for each actor their most organic acting ability including the use of sign language throughout the play.

The premiere of the play 'Carmen' was in the Hermitage Theater in Saint Petersburg, where Hose was performed by the deafblind actor Alexei Gorelov, The play 'Seagull' featuring a deafblind lead actress, was showcased at contemporary theatre festivals of art, receiving high reviews from theatre critics. A new play is being developed titled 'Hermitage: living paintings' This play is about the perception of art by deafblind people. Together deafblind and hearing and seeing artists will discover different ways of feeling and perceiving art. The premiere of this new play is planned for autumn 2017.

In the Accessible art laboratory, research and creative projects are developed that provide accessibility for deafblind people and

people with other sensory impairments to the fields of Fine Arts, Theatre and Cinema. We have developed a system to adapt theatre performances for an audience of individuals with deafblindness. We are now working on our own productions and experimenting with using sensory theatre for audiences with complex disabilities. In the new museum project at The Hermitage⁷, a team of experts from different fields of science and art as well as an inclusive group of artists are creating multisensory models of masterpieces on display at the famous museum.

The impact of these projects upon people with deafblindness is tremendous for several reasons. Firstly, the quality of life of those disabled participants involved in these creative artistic projects demonstrates such improvements as: feeling more independent, more respected, dignified and valued as artists. Secondly, due to high artistic level and originality of the performances, there is a mass media attraction and consequently a raising in social awareness of this disability. Finally, the focus on the idea of unity and inclusion results in a change in the social attitude towards disabled people away from rejection and avoidance towards a positive interest and a desire to communicate and know each other.

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From *Touchable*



From *Carmen*



From *Carmen*



From *Marriage*

⁷ Hermitagemuseum.oeg

South Africa **Experiencing Collegiality**

By Natasha Parkins-Maliko¹

DeafNET Centre of Knowledge (DeafNET)² hosted an Africa regional conference with its theme 'Deaf Education' in Johannesburg, South Africa in September of 2016. As an organization, DeafNet's main objectives are the describing, exchanging and dissemination of knowledge and expertise on issues relating to hearing loss among all persons with all types of hearing loss, including those totally Deaf, Hard of hearing and Deafblind.

At a conference for and of deaf delegates, such as the recent DeafNet conference, the important deliverable in my opinion was: *access to communication*, with the provision being to supply professional language practice professionals to ensure effective communication.

Having had access to the various sign languages operating throughout the 43 countries of Africa, I believe that my experience as an interpreter at this conference is worth explaining. Having worked with interpreting colleagues from across Africa and overseas with a wide array of skill sets and experiences has also provided me additional perspective about this issue.

There is no question that delivering interpreting excellence should be at all times a priority. Having said this, my experience has left me pondering over a specific interpreting question: "Do interpreters in Africa understand the skill sets required to interpret at an international conference alongside other sign and spoken language interpreters?"

There is much to understand about *collegiality* and how this term is understood and utilized in a conference setting of this nature, where there is a melting pot of cultures, values and behaviours. Interpreting colleagues are explicitly united in a common purpose and respecting each other's abilities is integral to that purpose. Our purpose at this conference was to ensure access to communication for all delegates; as such there is an unwritten rule of not engaging in the credentials of interpreter

colleagues. While there were obvious glaring differences in experience, qualifications and quality among the interpreters, these differences were put aside due to the respect for each interpreter's work space. Constructive feedback was shared among interpreters and there indeed was a sense of professional support. There was a sense also of understanding that we might differ; but we were united in our aim to deliver effective communication.

At the end of the conference I am excited with a renewed sense of pride in Africa and in the profession of interpreting on this large continent. Despite the hurdles experienced and the ones that lie ahead, I am positive that this continent can and will deliver excellent language interpretation to ensure that Deaf, Hard of Hearing and Deafblind persons are afforded equal rights to participate and engage in society.



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² www.deafnet.org

Participatory Curriculum Development to Meet Community Needs: Open Hands, Open Access: Deaf-Blind Intervener Learning Modules¹

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Human rights, human dignity and full participation in the world for all people, including people who are deafblind, are treasured ideals of Deafblind International. The mission of organizations like DBI involves the cultivation and sharing of community knowledge for the benefit of all. In this report, we share insights from a 4-year effort to develop a multimedia, open-access curriculum that was created with the involvement of over 220 collaborators, including family members of people who are deafblind, teachers, interveners, technical assistance personnel, interpreters, and people who are deafblind themselves. Although this initiative was based in the United States, the Canadian model of intervention is reflected in the thinking of the authors and within the learning activities. The name of this curriculum is indicative of the spirit of its creation: *Open Hands, Open Access: Deaf-Blind Intervener Learning Modules* or

OHOA⁷. The ultimate purpose of OHOA is to create deeper awareness, knowledge, and skills of the practice of intervention with students in their home communities.

Despite the diverse international approaches to defining the disability of deafblindness, there is globally acknowledgement that deafblindness is a unique disability, and people who are deafblind are both rare and heterogeneous (Nelson & Bruce, 2016). The experience of being members of a “rare” and complex disability group, combined with the very real challenges of having dual sensory losses, often means that children who are deafblind do not have access to educational staff members who know how to provide them with appropriate supports in local schools (NCDB, 2012).

Interveners – specially-trained paraeducators for individuals with deafblindness who provide environmental, communication, and social support within educational

and community settings – have been recognized by parents and professionals alike as unique personnel who provide high-quality direct support to individuals who are deafblind (McInnes, 1999; McCann, 2015). Although the intervener practice has been developing both internationally and nationally, most school systems do not formally recognize the role of interveners and there are few intervener training programs in the United States (NCDB, 2012).

The Need and Approach to the Open-Access Curriculum Design

In 2012, the National Center on Deaf-Blindness (NCDB), which is funded through a discretionary grant through the U.S. Department of Education, published recommendations to address the need for improving intervener services in the United States. Prior to making recommendations, NCDB staff engaged in focus groups, interviews, and analyzed

¹ Note: This paper was presented at Concurrent Session 17 (Education for children with visual impairment and additional/multiple disabilities or deafblindness), ICEVI Day Program (August 22, 2016), WBU-ICEVI Joint Assemblies, Orlando Florida

² <https://nationaldb.org>

³ paracenter.org/about/collaborations

⁴ www.afb.org · Find Services

⁵ www.georgebrown.ca/

⁶ www.wou.edu

⁷ <https://nationaldb.org/ohoa>

Participatory Curriculum Development



Amy Parker



Beth Kennedy



Donna Sobel



Gregory Zobel

surveys to describe the needs of a national community based on the perspectives of different stakeholders. One of the pervasive themes that was expressed by state deaf-blind projects and family members was the need for high quality training materials, including videos that could be used to increase awareness of effective approaches with students; standardize an understanding of the intervener role; and to serve as training tools that state or college systems could use to develop skilled interveners. Out of this dialogue, which included conversations with partners in the United States and Canada, the goal of developing a high-quality, standards-aligned, free resource for the community was established. For the full report on the 2012 *Recommendations for Improving Intervener Services* please visit this site: <http://interveners.nationaldb.org>

Despite the clearly articulated need for training resources, developing a curriculum that reflected recognized standards of practice for interveners as well as the diversity of individuals with deafblindness, presented several practical challenges. NCDB was charged with developing a free, high-quality resource that state, family and university partners could use to reach local groups of learners. An inclusive strategy was needed to both dialogue about the practice of intervention as well as to develop a high quality product with the community. Participatory approaches as methods for addressing complex societal challenges, such as in public

health or education, are often needed to bring a wide variety of people together to integrate both knowledge and action to create change (Taylor 2005). Participatory Action Research (PAR) has been applied as a “democratic” methodology that is based on intensive and strategic engagement with members of a community to define and address a shared set of challenges: drawing from the resources, values, strengths and innovations of the community to work to address shared needs (Akrofi & Parker, 2015). Within this participatory framework, NCDB anchored the community discussions of what an open access curriculum would represent with published knowledge and skills competencies from the Council for Exceptional Children for Intervenors (CEC, 2015; also see <http://community.cec.sped.org/dvi/professionalstandards>). This approach of using published standards as a discussion guide allowed NCDB to focus the conversation on module topics that would build specific knowledge and skills, as well as represent the rich diversity of students who are deafblind in examples, video narratives, and applied learning activities within OHOA.

The Community’s Development of OHOA

In September 2012, NCDB began hosting virtual meetings with various groups of stakeholders from state deafblind projects, personnel preparation programs, and family leadership organizations to incorporate various perspectives

into the module creation plan. Across each community group, repeated questions were asked about how multi-media modules might address local training needs. From these conversations, and from the findings within the recommendations process, a group of 19 network advisors was formed, with representation from all stakeholder groups, including family members, state deafblind projects, and university faculty. In October 2012, a face-to-face gathering was held with the 19 advisors to identify, align, and prioritize themes for the first eight modules according to the CEC standards and collective knowledge of the advisory group.

In addition to outlining module themes with respected advisors, NCDB sought counsel from experts at Perkins School for the Blind⁸, the University of Colorado at Denver’s Paraprofessional Resource and Research Center, and Vanderbilt University⁹, to glean insights on designing modules representing sound adult learning. Out of this collaboration with partners who had rich experiences in multimedia module design, a standard module template was crafted which could be used by lead authors and teams to create a flow and uniformity across all OHOA modules. Concurrently, NCDB sought advice from experts in online accessibility, captioning, video description, and technological platforms that could support interactive content use by partners

⁸ www.perkins.org

⁹ www.vanderbilt.edu



Mark Schalock



Ritu Chopra & Leanne Cook



Carolyn Monaco



Nancy Steele

who may have limited resources or technological infrastructures. Because of the community's desire to preserve its creative efforts and to share knowledge readily, accessibly and freely, the NCDB team talked with organizational partners who had used a variety of web-based platforms with varying success, particularly for individuals who rely upon screen reader software for accessing information. Moodle was selected as a learning management system for the modules because of its open source code, its international user support base, its stability, its relative accessibility for people who use screen reader software, and because modules created on this type of platform could be easily shared with organizational partners who can readily utilize Moodle installations if funding for the project were discontinued.

In November 2012, the content creation journey began with four multidisciplinary teams, which included respected content leaders, family members of individuals who are deafblind, teachers, interveners, consumers, educational interpreters and other related service personnel. These first teams worked over the course of an eight month creation cycle, with the support of NCDB staff, to produce content for nine modules. Although most of the content was produced using virtual meeting opportunities, two face-to-face gatherings allowed the teams to synthesize ideas, review teaching materials, create learning activities, and to develop high-quality video interviews in an onsite filming suite.

In December 2013, seven more multidisciplinary module teams were formed. Parents or other family members of people who are deafblind were recruited to offer more family members an opportunity to participate in the module creation experience and, through their involvement, to share new stories representing a greater diversity of students who are deafblind. Over the course of six months, the teams produced nine more modules with the support of NCDB staff. One face-to-face meeting was held to support efforts to create and align work.

The module creation cycle was repeated starting in December 2014, when a final eight teams were recruited and formed to write the last set of nine modules, which were released in September 2016. Over 77 diverse module authors and 220 collaborators were brought together across these three cycles of creation to produce a total of 27 multimedia modules.

Field Testing and Refinement

As each collection of modules was produced, NCDB engaged in field testing with interested participants across the nation. State deaf-blind project and university partners were invited to reach out to their networks of parents, teachers, and service providers offer the opportunity to "test drive" the modules for a set period of time. Those who signed up had opportunities to explore modules with and without instructors as a form of self-study. At the same time, NCDB invited subject matter

experts to use an evaluation protocol to review both the quality of the content, as well as offer their thoughts on the efficacy of the learning activities. After each cycle of field testing, evaluation surveys from participants who completed the modules and from experts who reviewed the quality of the content and learning activities were synthesized in order to make improvements in OHOA for future learners.

Open Hands Open Access: What Was Produced? How is OHOA Being Used?

From September 2012's first planning for the OHOA modules, through September 2016, the NCDB team, with its network partners, developed, field-tested, revised and released a total of 27 open-access modules. Within the module video repository, there are over 1300 interview or intervention video clips displayed within the modules, which align with the CEC's knowledge and skills competencies for interveners. Each module is structured around a template which is based on a synthesis of adult learning research, and represents 6–8 hours of engaged learning time.

At the time of this publication, there are 35 different state deaf-blind project partners and 7 university partners using the OHOA modules to teach diverse groups of people. There are over 5,100 users in the OHOA modules, which represent 93 different countries. Not all of the adult learners who are engaged in using the modules are interveners. Many are teachers or family

Participatory Curriculum Development



Photo of presentation in Orlando

members who are seeking additional professional development or ideas in providing supports to students who are deafblind. Since 2016, the development of the OHOA modules has supported the launch of one new intervener preparation program at Central Michigan University.

Four Lessons Learned from the OHOA Project

Although there were numerous lessons learned throughout the 4 year creation and implementation cycle, we will limit our scope to four core reflections from this effort.

Lesson 1 – Iterative Evaluation Allows Multiple Perspectives to Be Incorporated:

The process of reviewing data within this multilayered project, whether it is analytical data that is harvested from the Moodle system, or simply documentation from meetings with advisory leaders, has provided a strong framework incorporating the perspectives of several stakeholders into the design and use of the OHOA materials. This project's many collaborators and contributors have supported strong evaluation scores and positive comments from learners.

Lesson 2 – Leadership is Essential:

Colleagues planning to embark on large-scale, multi-faceted participatory initiatives such as

this will surely encounter the complexities associated with collaborative efforts (e.g., role assignment, communication, timelines, resource allocation, etc.). Only with strong leadership accompanied by clear, realistic guidelines and unrelenting support will the multiple pieces come together. The Office of Special Education Programs at the U.S. Department of Education provided national direction that supported the leadership of the National Center on Deaf-Blindness in coordinating the input of many diverse national, and a few international partners.

Lesson 3 – Incorporate Existing Knowledge Resources: While this effort appeared to be all-consuming, getting started and staying focused was helped by ensuring a focus on existing bodies of literature pertaining to professional standards and evidence-based practices. The creation and implementation of OHOA incorporated many existing resources and was aligned with published standards of practice. This foundation provided a framework for integrating and creating new information, reflections, and resources.

Lesson 4 – Face Time Still Matters:

Bringing module creation team members together for face-to-face meetings allowed the lead authors to more fully appreciate the knowledge, experience, and uniqueness of each module team member. This knowledge became an integral piece in allowing the leads to encourage the contributions of all authors and for developing authentic relationships. Contributors regularly expressed that while the virtual meeting were supportive of making progress, face-to-face meetings helped all members within the creative development process, allowing each person to contribute their perspectives more

fully, whether that was via video, in writing, or simply discussing creative ideas for learning activities. As team leaders brainstormed with their teams about the content, it allowed all module creators to see what was motivating to different individuals. This process would sometimes lead us to amend original module plans, resulting in what was later evaluated to be a better product.

Putting It All Together

The final OHOA module is an important one for this participatory curriculum project, both because of its celebratory and integrative themes for the practice of intervention as well as its synthesis of the previous module content. Because of the history of the intervener movement and the commitment of our Canadian neighbors to this vital practice, NCDB invited Professor Carolyn Monaco of George Brown College in Toronto to serve as lead author for OHOA Module 27 – Putting it All Together. Like all of the OHOA creation teams, Monaco's team included a family member, seasoned teachers, a university faculty member/researcher and technical assistance project staff. During the creation cycle which involved numerous virtual meetings and one face-to-face writing retreat, Monaco's team not only savored the opportunity to develop meaningful learning activities for interveners but enjoyed deepening their own knowledge of intervention through conversations. One such group conversation, led to a reflection on the practice of intervention as a challenging and satisfying journey, one in which interveners support their students/clients in overcoming obstacles to access. Inspired by one of Monaco's own students, who had written a reflection paper on the intervener's role, the group sought to use a popular song about overcoming challenges or "mountains" within

their module. The copyright challenges presented in pursuing permission to use the popular song turned out to be an unanticipated benefit, as Monaco's team was connected with TheSynthFreq,¹⁰ twin deafblind musicians Crystal and Danielle Morales, who composed a song based on the themes from their module group's discussion. The creation of an original song celebrating the work of a community in producing OHOA that was written by musicians who are deafblind represents a culminating moment in a multi-faceted, challenging and celebratory journey. Using a participatory approach, members of a diverse community co-created the Open Hands, Open Access Deaf-Blind Intervener Learning Modules as resource to address the needs of students who are deafblind where they live, where they learn, by sharing authentic and standards based knowledge about intervention with people that support deafblind individuals.

Please see the accessible music video with the music of The SynthFreq which has been translated into American Sign Language, captioned in English and is described for individuals who are blind or deafblind. (https://www.youtube.com/watch?v=_AQSrCNwEJI)

The Open Hands, Open Access: Deaf-Blind Intervener Learning Modules

The Open Hands Open Access (OHOA) Intervener Learning Modules are a national resource designed to increase awareness, knowledge, and skills related to intervention for students who are deaf-blind and are being served in educational settings (ages 3 through 21).

The module content was created by a diverse group of experts in the field of deaf-blindness including state and national deaf-blind project

staff, parents of children who are deaf-blind, higher education faculty, teachers, educational interpreters, deaf-blind leaders, and interveners. Each includes a variety of accessible videos, photographs, slide presentations, and learning activities. The modules have been guided by an advisory committee, and reviewed by a variety of experts in deaf-blindness and the process of intervention, experts in module design, and field-test participants.

Open Hands, Open Access: Deaf-Blind Intervener Learning Modules by NCDB (National Center on Deaf-Blindness) is licensed under a Creative Commons Attribution-NonCommercial 3.0 Unported License.

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For a list of all 27 modules and a downloadable brochure: <https://moodle.nationaldb.org/mod/page/view.php?id=24821>

Register for OHOA Modules at: <https://nationaldb.org/ohoaregister>

Each OHOA Module has a comprehensive list of references located within each module structure. Module readings and videos are all available within the OHOA Moodle system as open access resources and are free to all participants.

The contents of the Open Hands, Open Access: Deaf-Blind Intervener Learning Modules were developed under a grant from the U.S. Department of Education #H326T130013. However, those contents do not necessarily represent the policy of The Research Institute, nor the US Department of Education, and you should not assume endorsement by the Federal Government Project Officer, Jo Ann McCann.

For additional information, contact Amy Parker at: parkera@wou.edu

REFERENCES

- Akrofi, A., & Parker, A.T. (2015). An assessment project on the "literacy-on-the-job" needs of young adults in Sierra Leone. In P. Smith & A. Kumi-Yeboah, *Handbook of research on cross-cultural approaches*. Hershey, PA: Information Resources Management Association.
- Council for Exceptional Children (2015). *What every special educator must know: Professional ethics and standards*. Alexandria, VA.
- McCann, J. (2015). *Interveners and Children Who Are Deaf-Blind*, Retrieved from <http://sites.ed.gov/osers/2015/12/interveners-and-children-who-are-deaf-blind/>
- McInnes, J. M., (1999). Deafblindness: A unique disability. In J. M. McInnes (Ed.), *A guide to planning and support for individuals who are deafblind* (pp. 1–33). University of Toronto Press.
- National Center on Deaf-Blindness (2014–2016). *Open Hands, Open Access: Deaf-Blind Intervener Learning Modules*. Monmouth, OR: National Center on Deaf-Blindness, The Research Institute at Western Oregon University. Available at <http://moodle.nationaldb.org>
- Nelson, C. & Bruce, S.M. (2016). Critical issues in the lives of children and youth who are deafblind. *American Annals of the Deaf*, 161 (4), 406–411.
- National Consortium on Deaf-Blindness. (2012). Recommendations for improving intervener services. Retrieved from <http://interveners.nationaldb.org>.
- Taylor, Peter. (2005). How can participatory processes of curriculum development impact on the quality of teaching and learning in developing countries? *Background paper for the Education for all global monitoring report 2005: the quality imperative; Publ: 2004; 12p.*; 2005/ED/EFA/MRT/PI/47*.

¹⁰ <https://www.facebook.com/Synthtopia/posts/10152156623461956>

Quantitative Data Analysis

(Article #4 – Action Research in Deafblindness Series)

Susan M. Bruce

This is the fourth article in the action research in deafblindness series by members of the Action Research Work Group of the Deafblind International (DbI) Research Network. Action research, also known as practitioner research, is a problem-solving form of research in which the intervention and even the research questions may change in response to findings. While action research does not dictate design, some designs are more compatible to its principles than others. In this article we will address some of the most basic principles of quantitative analysis to support practitioner research across settings. Examples of studies are shared.

The purpose of data analysis is to “reduce vast amounts of data into smaller, more manageable sets of information” (Mertler, 2017, p. 171). In action research, the analysis of data should start as you implement your intervention, not at the end of the intervention. This allows you to reflect on your findings and to alter your intervention in response to findings. Hendricks (2017) suggests the following process for quantitative data analysis:

- Gather your quantitative data sources.
- Create displays of your quantitative data. Examples might include a line graph to show how prompting levels (across steps in a task analysis) changed over time, a bar graph to show the rate of a desired behavior across multiple students, or tables that display frequency counts of how often one student expressed various functions of communication.
- Ask a colleague to look at your displays to be sure they are understandable.
- Make notes about how each data source and display relates to your research question(s).

Practitioner-researchers will need to know at least some basic information about descriptive statistics and their application to action research studies. Key principles of descriptive statistics

include measures of central tendency, measures of variability, and measures of relationship (Mertler, 2017). *Measures of central tendency* include the mean (average of scores), the median, (middle score), and mode (most common score). For example, you might be recording how long a student stays on task. If she had a day or two with very low attention rates within a short data collection period, then the mean may not represent the usual rate of her on task behavior). In such a case, the mode (most common score) could be especially valuable. *Measures of variability* include the range of scores (as in from 4 minutes on task to 26 minutes on task), and the standard deviation (the score’s distance from the mean). Using the above example, if on task behavior varied greatly across tasks, reporting the range would be critical. Then, the team may look at the conditions that promote on task behavior and what interferes with it (perhaps by examining qualitative data collected).

You may want to use quantitative measures to determine fidelity of the intervention as well. Fidelity means that the intervention is being implemented (across people, time, or settings) in the way it was intended. Often we use checklists and calculate descriptive statistics. It is also possible to analyze some qualitative data by assigning

numerical values that then allow for calculation of descriptive statistics or perhaps just simple counts. For example, in conducting a study about a learner’s communication, the practitioner-researcher might decide to use videos transcripts to calculate the number of opportunities for communication created by communication partners. In the process of doing so, she might realize that the range across partners is large and seems to be related to either the role of the partner or the activity. This might result in further analysis. Understanding *measures of relationships* are statistics that demonstrate a relationship among variables, such as correlations and causation. Understanding the research designs that are associated with measures of relationships generally requires specialized coursework in educational measurement. The reader is referred to the reference section for texts that will provide much greater detail on quantitative data analysis.

Examples of Quantitative Analysis and Displays

Bruce & Vargas (2013) conducted a collaborative action research study to teach a young girl with visual impairment object permanence. A task analysis was used to list the instructional steps of the lesson.

“While action research does not dictate design, some designs are more compatible to its principles than others.”



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Three team members collected data each time the lesson was taught. This data was then tallied across the team members with a mean calculated for how the student performed the desired/ target behavior and with what level of prompting. In this article they include two figures that display these means. Intervention months appear along the X-axis and mean percentage of responses appears along the Y-axis. The figures display Jamie’s performance over time as well as the level of prompting required to elicit the desired behavior.

In his study of functional behavioral analysis and positive behavior supports, Faletra (2010) sought to understand the reasons behind his student’s head slapping behavior and what he could do to reduce it. He asked adult participants to complete the *Motivation Assessment Scale* (Durand & Crimmins, 1992) to determine their perceptions about why the student performed this self-injurious behavior. He then displayed how the mom, dad, and two teachers rated the behaviors and the mean across these four raters for each of four primary motivators of socially inappropriate behavior: sensory (including self-stimulation), escape (including task avoidance), attention, and tangible. In a second display, he presented

counts of head slapping in a graph with the X-axis representing the days before and during intervention and the Y-axis as frequency of head slaps. His displays allow the reader to interpret the impact of a sensory menu and sensory breaks on the reduction of head slapping.

Conclusion

Data analysis is a process that allows us to organize and draw meaning from the data collected. Carefully crafted data displays will support this process. Practitioner-researchers will benefit from knowing basic concepts associated with quantitative analysis including mean, mode, median, and range when interpreting their data. Some qualitative data can be quantified, such as when conducting simple counts of adult or child behavior drawn from qualitative data or when assigning a number to represent a specific behavior. When conducting action research, quantitative data analysis is an ongoing practice. This will allow the practitioner to change intervention practices in response to the data collected. Each change in practice then marks a new action research cycle. Team collaboration will be important to knowing when sufficient data has been collected and analyzed on a particular intervention and when it is time to adopt a new instructional practice.

REFERENCES

- Bruce, S. M. & Vargas, C. (2013). Teaching object permanence: An action research study. *Journal of Visual Impairment & Blindness*, 107, 60-64.
- Durand, V. M. & Crimmins, D. B. (1992). *The Motivation Assessment Scale Administration Guide*. Topeka, KS: Monaco.
- Faletra, J. (2010). Applying functional behavioral analysis and a positive behavior support plan to address self-injurious behavior in a student with severe disabilities. In S. M. Bruce & G. J. Pine (Eds.). *Action research in special education* (pp. 115-127). New York: Teachers College Press.
- Hendricks, C. (2017). *Improving schools through action research: A reflective practice approach*. Boston: Pearson.
- McMillan, J. H. (2008). *Educational research: Fundamentals for the consumer*. Fifth Edition. Boston: Pearson/Allyn & Bacon.
- Mertler, C. A. (2017). *Action research: Improving schools and empowering educators*. Fifth Edition. Los Angeles: Sage.

Developing a New Nordic Definition of Deafblindness

The first Nordic Definition of Deafblindness was developed in 1980, and accepted by the Nordic Board for Disability Issues, an expert team, answering to the Nordic Council of Ministers. Based upon function, it was an advanced definition at the time. For 25 years, it was accepted and used in many countries by professionals as well as by persons with deafblindness. This definition took an individual perspective as follows: **Deafblindness** is a combined vision and hearing impairment of such severity that it is hard for the impaired senses to compensate for each other. Thus, **deafblindness** is a distinct disability.

In the following years, some important actions undertaken by the international community made it clear that it was time for some changes. The United Nations accepted the adaptation of the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities¹ in 1993. The standard rules designate persons with disabilities as citizens who have the same rights and duties as other members of society. The UN declared that there were still barriers that restrain persons with disabilities to fulfil their rights and freedom.

During the 1990's, the Nordic Staff Training Centre (NUD)² took several initiatives to revise the definition, but eventually it all came to a standstill when the parties involved were not able to agree.

In 2001, WHO³ endorsed The International Classification of Functioning, Disability and Health (ICF)⁴. It offers a four-dimensional framework for describing and organizing the main components of a disability. In addition to the impairment, assessment of the individuals functioning and participation within their environment are taken into account.

When the Nordic countries, initiated by NUD, started to revise the definition of deafblindness in 2004, everybody agreed that the definition had been very important up until that time, and had fulfilled its role. With the UN standard rules and the ICF we tried to revise the definition in order to keep it in line with a more modern view of people and disability policy.

With influence from both practice and the documents mentioned above, a committee created a definition consisting of two sentences, which paid attention to those concepts from ICF concerning activities and participation. The initial suggestions for a revised

definition was put out for a field trial. Feedback from the field trial resulted in a revised definition accepted by the Nordic Leaders' Forum in 2007 as the revised Nordic definition.

At the same time, there was voiced after some years there should be an evaluation of the functionality nature of the definition. The Leaders Forum decided in 2013 that it was time for an evaluation of the definition and recommended that a working group be established to undertake this project. The working group was made up of experts in the field of deafblindness representing the Nordic Countries as follows: Estella Björnsson⁵ (Iceland), Ritva Rouvinen⁶ (Finland), Marianne Disch⁷ (Denmark) and replaced by Henriette Hermann Olesen⁸ (Denmark), Trine Seljeseth⁹ (Norway) and Helene Engh¹⁰ (Sweden). Maria Creutz¹¹ (Sweden), later became an associated member of the working group. Knut Johansen¹² (Norway) was asked to lead this work.

The Leaders' Forum accepted the initial working groups' recommendation that the definition should be revised. It advised the working group to continue this work, with the addition of Linda Eriksson

¹ www.un.org/esa/socdev/enable/dissre00.htm

² NUD was created in 1981 by the Nordic Council of Ministers. It ceased to exist after it merged with several Nordic organization to become on January 01, 2009, the Nordic Centre for Welfare and Social Issues (NVC- www.nordicwelfare.org)

³ www.who.int

⁴ www.who.int/classifications/icf

⁵ Icelandic National Institute for the Blind, Visually Impaired (www.midstod.is) is small corporate member of DbI.

⁶ The Finnish Deafblind Association (www.kuurosokeat.fi) is a small corporate member of DbI.

⁷ Formerly with the Denmark National Board of Social Services www.socialstyrelsen.dk/handicap/dovblindhed

⁸ The Center for Deafblindness and Hearing Loss, Denmark www.cdh.m.dk is a small corporate member of DbI.

⁹ Norwegian National Advisory Unit on Deafblindness (www.dovblindhet.no)

¹⁰ The Swedish Resource Centre for Matters Regarding Deafblindness (www.nkcdb.se) is a small corporate member of DbI.

¹¹ Nordic Centre for Welfare and Social Issues(www.nordicwelfare.org) is a small corporate member of DbI.

¹² Signo Dovblindesenter (www.signodovblindesenter.no) is a small corporate member of DbI.

“Deafblindness is a combined vision and hearing impairment of such severity that it is hard for the impaired senses to compensate for each other. Thus, deafblindness is a distinct disability.”

representing the Deafblind Nordic Cooperation Committee¹³.

The task then was to propose a revised definition that should be simpler and easier to read. The group undertook a field trial to examine different options to present the definition’s text. After deciding on the best option, numerous English-speaking colleagues from USA, Great Britain and Australia were consulted along the way to ensure a fluent English language. A final meeting took place in September 2015 to finalize the new definition.

The new Nordic Definition of Deafblindness – approved June 2016

Deafblindness is a combined vision and hearing impairment of such severity that it is hard for the impaired senses to compensate for each other. Thus, deafblindness is a distinct disability.

Main implications

To varying degrees, deafblindness limits activities and restricts full participation in society. It affects social life, communication, access to information, orientation and the ability to move around freely and safely. To help compensate for the combined vision and hearing impairment, the tactile sense becomes especially important.

On the combined vision and hearing impairment

The severity of the combined vision and hearing impairment depends on:

- the time of onset, especially in relation to communication development and language acquisition
- the degree and nature of the vision and hearing impairments
- whether it is congenital or acquired
- whether it is combined with other impairments
- whether it is stable or progressive

On the distinct disability

The fact that it is hard for the impaired senses to compensate for each other means that:

- Attempting to use one impaired sense to compensate for the other one is time consuming, energy draining and most often fragmented.
- A decrease in the function of vision and hearing increases the need for making use of other sensory stimuli (i.e. tactile, kinaesthetic, haptic, smell and taste).
 - It limits the access to distance information.
 - It creates a need to rely on information within the near surroundings.
 - To create meaning, it becomes necessary to rely on memory and to draw conclusions from fragmented information.

On activities and participation

Deafblindness limits activities and restricts full participation in society. In order to enable the individual to use their potential capacity and resources, society is required to facilitate specialized services:

- The individual and their environment should be equally involved, but the responsibility for granting access to activities lies on society. An accessible society should at least include:
 - available competent communication partners
 - available specialized deafblind interpreting, including interpreting of speech, environmental description and guiding
 - available information for everyone
 - human support to ease everyday life
 - adapted physical environment
 - accessible technology and technological aids
- A person with deafblindness may be more disabled in one activity and less disabled in another activity. Variation in functioning might be the consequence of both environmental and personal factors.
- Specialized competence related to deafblindness, including an interdisciplinary approach, is vital for proper service provision.

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¹³ www.fsdb.org

A Fascinating Interview with Lea Hyvarinen

Dateline August 20, 2016, Orlando Florida

Upon arriving in Orlando this past August to attend the DbI Board and ManCom meetings, a request was made by past DbI President William Green to interview Dr. Lea Hyverinen for an article for DbI Review. I knew of Dr. Hyverinen as my organization¹, the Canadian Deafblind Association, had published her book ‘Vision in Children-normal and abnormal’ in English in 1988.

Subsequently, Dr. Hyverinen and I met in the busy corridor of the vast Rosen Hotel, which was for some days the location of the quadrennial meeting of ICEVI. For the next hour I was mesmerized through listening to a brief glimpse into the lifetime of one of the world’s legends in the field of vision assessment, rehabilitation, deafblindness etc.

The following is my sketchy attempt to trace Dr. Hyvarinen’s fascinating career based on our interview and confirmed through further details obtained from the internet.

Dr. Lea Hyverinen was born in Jyvaskyla in Eastern Finland in the early 1940’s. She attended a Finnish Girls School where they trained girls to be good academic citizens as well as good housewives. Not surprisingly, Lea demonstrated much

more ambitious intentions compared to school’s objectives, when in her early teens she had the ambition to become an eye doctor. Eventually she attended the University of Helsinki, training as an ophthalmologist, her early teenage ambition. The subject of her doctoral dissertation was the development of a new technique called ‘Experimental Fluorescein Angiography’ (EFA)², a methodology which provided new insights into the negative impact on vision resulting from of diabetic retinopathy and retinitis pigmentosa (RP)³.

With her doctorate in hand, Dr. Hyvarinen’s international career began in full swing. First she was invited to the USA to set up an EFA laboratory at the Wilmer Eye Institute, connected with the famous

John’s Hopkins Hospital in Baltimore Maryland. Those early years (1969–1971) in the USA strongly influenced what would become her outstanding career in vision assessment and rehabilitation (and more).

Dr. Hyvärinen returned to Finland after two years in the USA to work with her late husband Juhani Hyvärinen’s research group at the Institute of Physiology at the University of Helsinki⁴ (1971–1983) on visual deprivation studies of monkeys. These investigations showed that early vision deprivation permanently changes the function within the neural networks normally combining visual information with other sensory information. These studies helped form her theoretical concepts as the basis for her early vision intervention techniques. Based on these collaborative

¹ www.cdbanational.com

² ophthalmology.med.ubc.ca

³ https://nei.nih.gov/health/pigmentosa/pigmentosa_facts

⁴ <https://www.helsinki.fi/en>



“... I was mesmerized through listening to a brief glimpse into the lifetime of one of the world’s legends in the field of vision assessment, rehabilitation, deafblindness etc.”

studies on monkeys together with her husband, Dr. Hyvärinen’s approach has been that new born babies need visual stimulation from birth; it is never too early to intervene with young children if there is any indication of early visual problems.

Among many accomplishments, Dr. Hyvärinen is probably best known for the LH Vision Test System, now known as LEA TEST VISION SYSTEM™⁵. The LH Symbols tests (now referred to as LEA SYMBOLS® tests) became popular in 1980’s for vision screening, continue to be used for assessment of vision in children.

Well known within the deafblind field in the Nordic Countries, Dr. Hyvärinen was a member of the task group that planned the teaching program at the former Nordic Staff Training Centre for

Deafblind Services (NUD) in Dronninglund (Denmark) and lectured (1980–1987) in ophthalmology at the Centre. She was part of the working group which developed the first Nordic Definition of Deafblindness ⁶ in 1980. This definition, advanced at its time, was accepted and used in many countries by professionals as well as by persons with deafblindness.

Following this period, Dr. Hyvärinen spent a sabbatical (1987–1988) at the Smith-Kettlewell Institute in San Francisco, CA where she wrote a book on communication based on her assessment of deafblind individuals using an excellent intervenor.

This is just a small sample of Dr. Hyvärinen’s life time work. For much more detail check out her website (www.lea-test.fi) which details her employment activities,

list of awards and titles of 285 publications she has authored over her career.

I had the privilege of attending a workshop “Effect of vision loss on communication and social skills” presented on August 22, 2016 during ICEVI Day at the WBU-ICEVI Joint Assemblies 2016 in Orlando Florida. She still commands an audience and continues to demonstrate she is still a force in her chosen field.

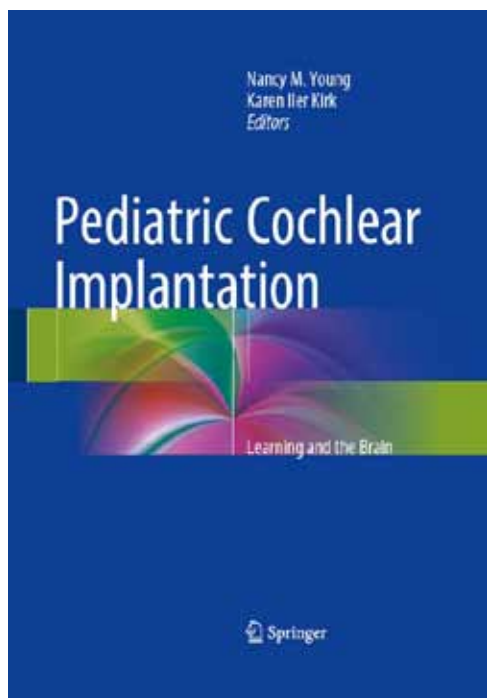
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⁵ www.lea-test.fi/en/vistests/instruct/LEA_Vision_Test_System.pdf

⁶ See this definition described in another article in this edition of DbI Review



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DbI Board Membership 2015–2019

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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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Secretariat News

CHANGE IN SECRETARIAT

It is with a heavy heart that we must inform you that Senses Australia has given notice to return the secretariat to DbI. Senses Australia has held the secretariat for 8 years and we have benefited enormously, as have the Australian deafblind community, but it is time that we give others the opportunity to be at the forefront of international deafblind services. Senses Australia is still committed to DbI and will remain engaged through our seat on the Board and will continue our participation in DbI conferences.

MEETINGS

On 21 and 22 August 2016, the DbI Board and the Management Committee met in Orlando, Florida, USA to coincide with the WBU-ICEVI Joint Assemblies. Key areas that were discussed were:

- The 2015–2019 Strategic Plan
- The DbI Constitution
- DbI Networks

We were very pleased that Geir Jensen, President of the World Federation of the Deafblind, Lord Colin Low, President of ICEVI (now Immediate Past President), and Dr M.N.G. Mani, CEO of ICEVI were able to participate in the Board meeting and share their organisations priorities and challenges.

MEMBERSHIP

DbI recognises that the success it achieves worldwide greatly depends upon the support of its individual and corporate members to promote awareness and services. Becoming a member of DbI is very easy to do. Memberships may be purchased online through our website (www.deafblindinternational.org) or by contacting the Secretariat.

A summary of the membership per region is outlined below:

	Large Corporate	Small Corporate	Mini corporate	Individual	Library
Europe	9	32		76	2
North America	3	6		42	3
South/Central America		2		4	
Oceania	2	3		6	1
Asia		3		11	
Africa			3	3	2
TOTAL	14	46	3	142	8

CHANGES TO THE BOARD

There have been a few changes to the composition of the Board since our last meeting in Bucharest. Unfortunately, the National Board of Social Services (Denmark) has indicated that they no longer wish to hold the DbI Board seat. As a result, we are VERY pleased to announce that Association Nationale pour les Personnes SourdAveugles (France) has accepted this vacant Board seat and Dominique Spriet will represent this organisation.

Other changes include Dennis Lolli relinquishing his position on the Board for Perkins International and being replaced by Marianne Riggio. Dennis will continue his role on ManCom as Diversity Officer.

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



@DeafblindInt

Old fashioned email:

secretariat@deafblindinternational.org

Become a member by contacting us.



**Matthew Wittorff and Bronte Pyett
DbI Secretariat**

Proudly hosted by
Senses Australia



DbI Mancom, Orlando, 2016



Colin Low (L) and
MNG Mani (ICEVI)



Geir Jensen and interpreters
(WFDB)



DbI Board Meeting in Orlando



DIVERSITY



NETWORKS



SOCIAL MEDIA

STRATEGIC PLAN

JUN 2015 - AUG 2019



DEAFBLIND INTERNATIONAL



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

Deafblind International (DbI) Awards

ANNOUNCEMENT

The months are moving along and it will soon be time for the 2017 European DbI Conference September 5–8, 2017. The Conference brings together colleagues from all over Europe and around the world for learning, sharing and celebrating. At DbI regional and world conferences we have the privilege of honoring people who have made exceptional contributions to individuals who are deafblind and to DbI. We are soliciting nominations for the Young Professional Leadership Award, the Distinguished Service Award and the Lifetime Achievement Award to be given out in Aalborg, Denmark. I hope you will take time to review the criteria for the awards and to submit names for consideration. Please submit your nominations using the process outlined.

All nominations must be received by **May 12, 2017**

Please email the nomination packet to Bernadette Kappen at bkappen@nyise.org for review by the Awards Committee. Faxes will not be accepted.

DbI International Young Professional Leadership Award Eligibility Requirements

DbI has created the Young Professional Leadership Award to honor individuals younger than 40 years of age who are providing high quality program opportunities.

Nomination Criteria:

- Recognition as an up-and-coming leader in the field of deafblindness
- Demonstrated excellence, creativity and initiative in their work
- Provides valuable service to improve the quality of life for individuals who are deafblind
- Potential of future impact of nominee's work in the field of deafblindness

The nominator should provide a descriptive summary of the nominee's achievements and contributions in 500 words or less. The summary should provide specific examples which attest to each of the four criteria. The nomination submission must also include a minimum of two letters of support from colleagues, parents or consumers. If the nominee is a teacher, one letter should be from a parent and if the nominee is an administrator one letter of support should be from someone outside the person's agency, i.e. ministry of education or another outside organization.

DbI Distinguished Service Award Nominee Eligibility Requirements

This award recognizes a DbI member who has significantly contributed to the deafblind field or DbI, internationally.

Examples of work in the deafblind field or within DbI.

- Examples of contributions when thinking about a possible nominee for the Distinguished Services Award: 1) overall professional experiences; 2) innovative practices; 3) unique or extraordinary contributions to DbI; 4) professional publications, research and/or staff training activities; 5) leadership on the international level which has promoted or improved services to deafblind individuals and their families.

DbI Lifetime Achievement Award Eligibility Requirements

The Lifetime Achievement Award will be made to an individual who has made a distinguished contribution to services for deafblind people on a national and international level.

- This award is recommended to be given towards the end of one's working career.
- Distinguished contributions could be in the area of: publications, research, development of new techniques or procedures, practical application of teaching techniques, training staff and parents, advocacy; and dynamic leadership.

“At DbI regional and world conferences we have the privilege of honoring people who have made exceptional contributions to individuals who are deafblind and to DbI.”

INSTRUCTIONS for Nomination for the DbI Distinguished Service Award and the Lifetime Achievement Award

1. Complete the nomination form.
2. Attach a 500 to 1000-word essay, which describes the nominee's contribution to deafblind individuals.
3. Attach at least three (3) letters, which support the nomination. These letters can be from colleagues, parents, deafblind individuals, employers or others who can comment on the nominee. The letters should present information that conveys an accurate picture of the nominee's achievements and contribution to the field of deafblindness.



DbI Young Professional Leadership Award, Distinguished Service and Lifetime Achievement Awards

NOMINATION FORM

Please type the following information so that it can be easily read or scanned. Forms or letters not presented in this manner will be returned.

I would like to nominate: *(Please complete a separate nomination form for each award/nominee)*

Name of nominee: _____

Address: _____

Telephone Number: _____ Email: _____

Is this individual a current or past member of DbI? Yes? No

For the following award: *(Please check one)*

- Distinguished Service Award
- Lifetime Achievement Award
- Young Professional Leadership Award

Name of nominator: _____

Address: _____

Telephone Number: _____ Email: _____

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

and stress control in the MDVI Curriculum' and 'Participatory Curriculum Development to Meet Community Needs'.

Perkins International, through its article 'Responsible Inclusion', trace its commitment to advocating for the advancement of the education, economic and political rights of all children and adults who are blind and visually impaired with additional disabilities, including deafblindness.

In the 'Peace of Mind' article, the author indicates a growing awareness that mindfulness tools and techniques can be especially relevant when working with young people with Multi-Disabled Visually Impairment and Deafblindness.

The 'Participatory Curriculum Development' article outlines a 4-year effort to develop a multimedia, open-access curriculum in the USA through the involvement of over 220 collaborators, including family members of people who are deafblind, teachers, intervenors, technical assistance personnel, interpreters, and people who are deafblind. The authors report that the Canadian model of intervention is reflected in the thinking of the authors and within the learning activities.

Two other feature articles: 'The importance of the bodily-tactile modality for students with congenital deafblindness who use Augmentative and Alternative Communication (Schou et.al)' and 'Gestures

in Augmentative and Alternative Communication (Comenisch et.al)' offer interesting points of view about alternative language development.

According to Schou et al., children with congenital deafblindness have, in common with other children, youth and adults who completely or partially lack functional formal language, the need for alternative and/or supplementary forms of communication (AAC) in order to make themselves understood. The study of the bodily tactile contribution to language development in students with congenital deafblindness (an emerging field of study) is considered essential for the development of their understanding, conceptual learning and cognitive abilities as well as being a foundation for their relations with their seeing and hearing partners.

According to Camenisch et al., children can communicate using their body from birth onwards. Of all their body-parts, the hands are especially helpful and expressive. If spoken development does not happen or is delayed, their hands continue to offer an important way of developing communication. This is why gestures and hand signals are some of the

most important techniques of Augmentative and Alternative Communication (AAC).

In addition to the larger feature articles, this edition follows the magazine's tradition of presenting brief reports from the following DbI Networks: CHARGE, Communication, Youth, Outdoor, Usher Syndrome and Research.

As well, other submissions are organized in the section titled Country Reports. In this edition, articles are published from Africa, Australia, Brazil, Canada, Ireland, Germany, France and Russia. I want to highlight the article from the Russian Deafblind Support Foundation 'Con-nection' titled: From Exile to Stage-The story of Deafblind People Becoming Artists. It's a thoughtful article with some fascinating photos of various theatre productions featuring actors who are deafblind.

Conferences continue to be an integral activity of DbI. By publication time, we will be about six months away from the 9th DbI European Conference (Touch of Closeness) scheduled in early September 2017 in Aalborg, Denmark. Three of the Networks (CHARGE, Youth and Usher Syndrome) are planning pre-conference events. There are further details about the main conference and the pre-conference events in this edition.

Respectively,
Stan Munroe,
January 2017

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 sponsorship to the *DbI Review*. The Secretariat will inform applicants of the outcome of their request for sponsorship following a decision by ManCom.

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

Sponsorship Levels, Costs and Entitlements of *DbI Review*

Level 1 Sponsorship = 8000 Euro

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

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

Level 2 Sponsorship = 4000 Euro

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

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

Level 3 Sponsorship = 2000 Euro

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

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



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

Successful Applicants

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

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

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

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

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