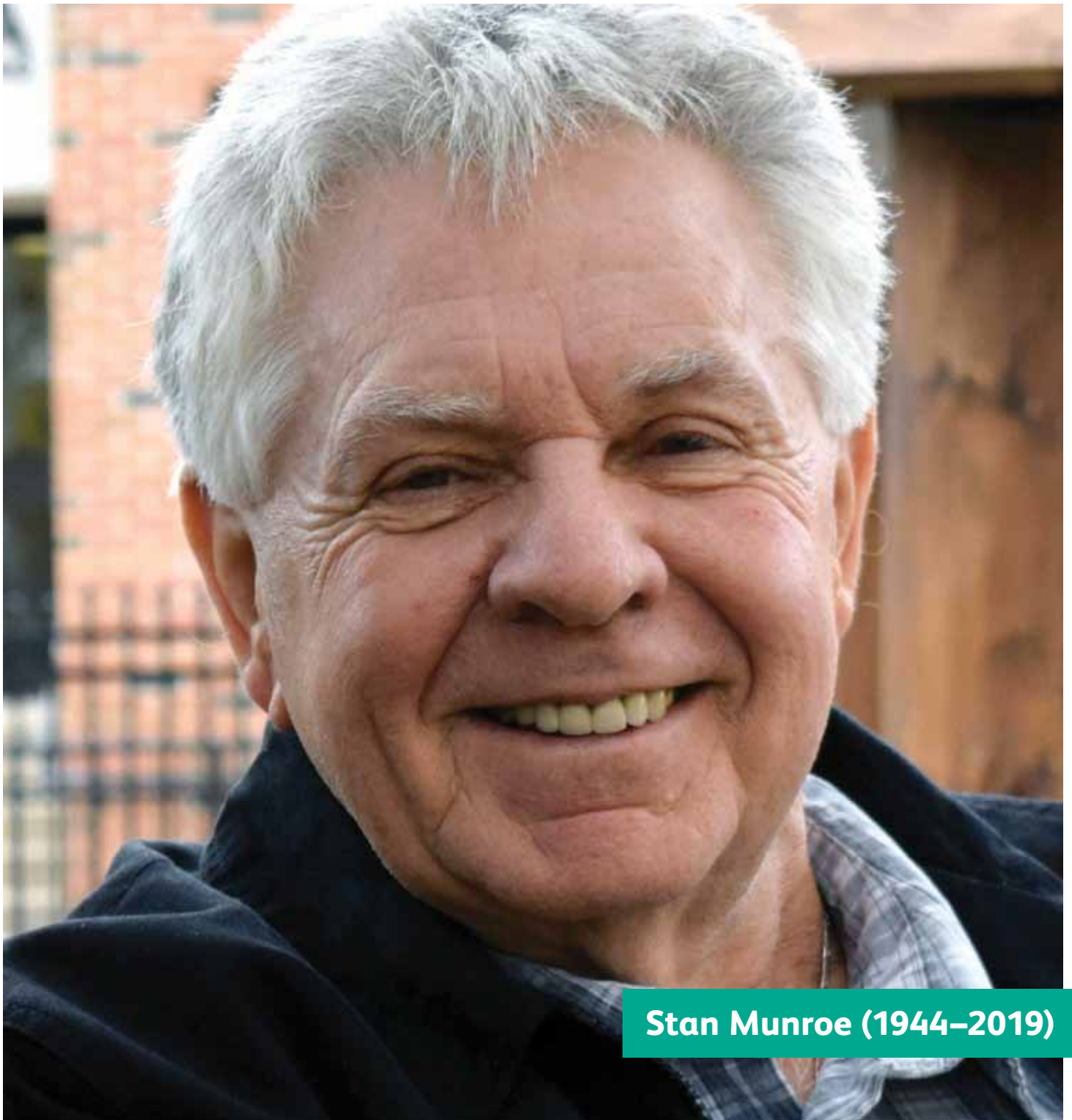


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INTERNATIONAL

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Review



Stan Munroe (1944–2019)

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, notices of books and information on forthcoming events, such as conferences and courses. Photographs are welcome – preferably not from digital cameras.

All written material should be in the English language and may be edited before publication. It should be sent for publication to arrive by the date below.

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

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DbI Secretariat
Able Australia, Camberwell
Email: gary.daly@ableaustralia.org.au
Tel: +61-8-94735451
Facsimile: +61-8-94735499

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Editor
Stan Munroe

Design
Sally Coleman

Distribution, DbI Membership, and DbI Website
DbI Secretariat and DbI Treasurer
Email: secretariat@deafblindinternational.org

DbI Website
Secretariat

Editorial Office
Submissions for the DbI Review Edition 63 should be forwarded to: Carolyn Monaco – Canadian Deafblind Association
Email: carolyn.monaco@sympatico.ca

Website: www.deafblindinternational.org

Cover: Stan Munroe, Editor DbI Review (2011–2019)

Dear Friends and colleagues,

As I start this introduction, I think we are all deeply affected by the loss of Stan Munroe. Stan was one of those special people who was always smiling and probably known to everyone in DbI. Of course Stan worked tirelessly on our DbI Reviews and created an inclusive and well respected magazine, recording the amazing achievements of DbI and our wonderful membership.

Sadly we also lost Sharon Barry Grassick and Professor Maria-Bitner Glindzic. Their obituaries are included in our Review and will be remembered by all for their dedication and contributions to DbI. Our condolences are extended to their families.

I know Stan, Sharon and Maria-Bitner would want us to turn to the future so all the more important that we feedback on the Young Researchers Conference held in Moscow October this year. Huge thanks must go to Frank Kat who was instrumental in organising and of course Dmitry Polikanov and his team in Con-nection. It was a joy to meet young inspirational people with so many brilliant ideas. This is a model we hope we can repeat in the future. Supporting the rising stars of the future must be a key thing DbI should do.

It was therefore a joy to have Simon Allison from the DbI Youth Network with us. We viewed the video, largely made by the young deafblind people themselves. Just wonderful with a few tears as we viewed such fantastic footage.

Of course we also held our Management Committee, Board and AGM. They were busy meetings as we discussed budgets, finance, continuing to increase social media, improving the website along with network and conference planning.

Huge thanks must go to Roxanna Spruyt-Rocks, and the scientific committee along with Kate MacRae (CEO Able Australia and Chair of Planning Committee).

The work around the world conference in Australia is 'picking up pace'. Gary, as well as his secretariat duties, is also working hard on the conference.

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At the time of writing we are preparing for nominations, new officers, Board and Management committees. The nominations committee is doing a great job as we prepare for change and the next 'era' of DbI.

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As I start this introduction, I think we are all deeply affected by the loss of Stan Munroe. Stan was one of those special people who was always smiling and probably known to everyone in DbI.

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We used the equivalent of Skype (Zoom) and were able to bring six countries and Board members into the meeting simultaneously with no 'down time'. This is technology we will use again and members will see how useful this will be for diversity and including people from other continents so great stuff. 'Hats off' to Roxanna and Cathy Proll particularly, as Canadian colleagues, who basically stayed up most of the night to join us. We of course missed William Green as our Past President.

Frank Kat has done a great job in the Treasury role and Kentalis, through Maria Brons and Trees van Nunen-Schrauwen, who continue that legacy with our budgets and finance. There are some challenges as organisations face funding issues but we are delighted that the majority of our large corporates continue to support the international deafblind mission.

At the time of writing we are preparing for nominations, new officers, Board and Management committees. The nominations committee is doing a great job as we prepare for change and the next 'era' of DbI.

Our Management committee will meet in Africa at the beginning of 2019 but hope many of us will catch up in Australia in August.

With Best Wishes,
Gill Morbey, President



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Vice Presidents' Messages

BERNADETTE KAPPEN REPORTS:



Achieving a goal of greater inclusion has always been something that DbI has focused on. We have made progress in this area with the expansion of our social media efforts over the past two years. The regional conferences have seen an increase in the number of participants. This includes participants from a variety of countries around the world. DbI is committed to diversity among its members and participants at various events. One of the main strategic goals is focused on diversity and this is being looked at in all activities.

In April, DbI sponsored the Network of the Americas Conference hosted by Perkins School for the Blind. This was the first time in twenty years that a conference was held in the United States. Hyannis was the setting that drew over 400 participants from around the world. The conference offered topics for professionals, parents and family members and individuals with deafblindness. In this setting the diversity was aimed at including all individuals involved in the lives of individuals with deafblindness. The richness of the topics and the social experiences created a magical learning environment.

Currently the main activity for DbI is planning the World Conference in Australia. The selection of Australia as a host had the intention of bringing more participants from Asia and the South Pacific region. The Scientific Planning Committee has been working on developing a program that will focus on the topics of accessibility, communication and technology. In looking at these areas diversity has been a key component. I encourage you to participate in the conference and be a part of one of the most dynamic group of individuals working in the field of disabilities. The spirit of DbI is one that is very special and everyone feels included.

At the conference we will have an opportunity to celebrate the achievements of individuals at the awards ceremony. This is the time to honor your colleagues who have demonstrated outstanding work in the field. DbI presents three awards: Lifetime Achievement Award, Distinguished Service Award and Young Professional Leadership Award. Information on how to nominate an individual for an award can be found on the DbI website. DbI also provides limited number of sponsorships to attend events. If you are interested in being considered for sponsorship to attend the World Conference, you can find the sponsorship information on the DbI website. The sponsorship covers registration and accommodation at an event.

In closing, I encourage you to help with the diversity efforts by sending information for the website, share stories and pictures on Facebook, Twitter, Instagram and writing articles for the DbI Review.

Bernadette M. Kappen
(bkappen@nyisi.org)

“
DbI is committed to diversity among its members and participants at various events. One of the main strategic goals is focused on diversity and this is being looked at in all activities.
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FRANK KAT REPORTS:



Looking back at 2018 I see a lot of activity going on, especially the fact that two special conferences occurred in one year. The first event was the Network of the Americas Conference. This was an excellent cooperative effort between Deafblind International and Perkins School for the Blind

together hosting the first-ever Network of the Americas Conference. This was a great opportunity to network, learn and have fun with leaders in the field of deafblindness from North America, Central America, South America and the Caribbean. This was a conference where Lifelong Learning was discussed, presented and made possible.

The other conference was also a unique event. The issues related to deafblindness are normally the matter of concern for active deafblind professionals; but it does not happen very often that they turn into academic studies. The DbI strategy encourages diversity as one core focus of its efforts. This is why it is important to host conferences in all parts of the world; in this latter case – Moscow, October 2018. The talented young participants were from many different Russian regions representing 4 continents. The Scientific Committee for this Young Researchers Conference was able to establish a challenging and interesting program with the theme, ‘Generating New Knowledge and Improving Practice.’

This was a unique opportunity to share experiences and to create an international network for young scientists, working within an interdisciplinary manner to meet the demands and challenges required in the field of deafblindness. Not only did young and enthusiastic newcomers attend this event, but also experienced senior well-known players in the field were there to interact. And I do hope that this International Young Researcher’s Conference will turn into a regular event.

We have many challenges ahead. As the deafblind population becomes increasingly represented by multiple disorders, new technological developments requiring specific skills need to be integrated into the education and rehabilitation program for this population. This is why DbI needs to continue to rethink its strategy.

It is time now for DbI to find additional suitable partners from a wider field where DbI is able to add its experience, networking capability and knowledge to become even more effective. Because not only do we face new challenges, but old ones appear in new areas. Together we can make a difference.

Frank Kat
(Frank.Kat@outlook.com)

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As the deafblind population becomes increasingly represented by multiple disorders, new technological developments requiring specific skills need to be integrated into the education and rehabilitation program for this population.
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Can the assessment and development of sign language competence lead to an externalisation of a mental disorder and promote sociality?

An interdisciplinary socio-educational project

Ole Wøssner



Preface

In December 2015, we welcomed a new resident to Døvblindehuset (House of the Deafblind): a young woman whose family had requested that she be moved to a residential facility closer to the family home. We had known the woman for several years, but had not previously had the right physical setting to provide an adequate home for her.

Suddenly, the opportunity arose, and we put together an offer and prepared, as well as we could, to welcome her to our facility.

The young woman has faced major challenges in life, especially in her interactions with others, due to a mental disorder that manifested when she was around 8 or 9 years old.

For many years she has displayed violent behaviour, conditioned by her mental disorder and

communication difficulties. When she was transferred to Døvblindehuset, we received a status report from her previous residential facility, which devoted significant attention to her preoccupation with an imaginary 'dangerous man'. This man was a persistent and recurring focus for her, and at times he dominated her communication with the educators completely.

In our planning, we focused on making sure we would be able to offer the necessary sign language competences. Hence, the team included two experienced staff members from Døvblindehuset and two deaf staff members.

The 'dangerous man' was an expression of her hallucinations and psychotic states, during which she repeatedly described seeing the 'dangerous man'. Often she was able to point to the place in the room where she saw him. It proved extremely difficult for

us to have her add any nuance to the way she talked about and described the 'dangerous man', and in some cases she displayed repetitive anxious behaviour that could be exceedingly difficult to break.

On several occasions, the staff asked her to draw the 'dangerous man', but there was no consistency to these illustrations. Thus, we have to assume that her hallucination does not have a fixed form or face, or, perhaps, that she has several images of the man, possibly related to her current state of mind.

Purpose, hypotheses and goals

Jane's initial time at Døvblindehuset was fairly turbulent. She had to be hospitalized for an extensive period due to a somatic condition, and after this period, she was very troubled by her mental disorder. Hence, our educational approach was not very successful, and we needed to find an alternative approach that would allow us to get around or 'behind' her psychiatric condition and promote freer communication.

We contacted the psychologist at CFD (formerly known as Centre for the Deaf)¹ and based on several meetings and supervision sessions, we decided to initiate the project. The project aims to help Jane externalize her condition in order to develop the awareness that although her hallucinations seem real to her, they are not visible to anyone else – in fact, they are a product of her mental condition.

Our general hypothesis was:

- By externalizing her mental disorder, Jane will be able to reduce her preoccupation with her hallucinations and maintain her grip on reality and, over time, improve her ability to socialize with her surroundings.

This general hypothesis was based on two sub-hypotheses:

- By using sign language to synchronize our responses to Jane's sign communication about her hallucinations (externalization), we will be able to reduce the occurrence of psychotic states.
- An assessment of Jane's sign language proficiency will enable a more nuanced and relational approach, allowing reality to play a larger role in our interactions.

Goals and success criteria:

- We obtained an overview of Jane's use of sign language when she speaks about her psychosis and hallucinations, which will give us some degree of confidence in our decoding of her language.
- A visible reduction in the occurrence of hallucinations and psychoses.

- A visible reduction in the occurrence of episodes where she acts out.

These are very specific and measurable success criteria, which also address the behaviour that has historically constituted Jane's main challenges in interactions with her partner.

Externalization – synchronization of responses/sign language use

The first project activity was a supervision session on 27 October 2016 overseen by a CFD-psychologist.

Here we discussed Jane's hallucinations and psychoses and what our responses should be when she brings these up in her communication with us. At the time, this occurred on almost a daily basis, sometimes continuing for hours, with a persistent and insistent communicative focus on the 'dangerous man'. She would repeat the same sentences over and over again and was clearly worried and upset.

In this supervision session, we developed the first guidelines for our approach to Jane's psychoses and made our first attempts at synchronizing our responses to her when she was upset and repetitive. The guidelines are included in the summary below from the supervision session:

Summary from the supervision session on Thursday, 27 October 2016:

The following general guidelines apply to our interactions with Jane:

- We acknowledge what Jane sees – affirming what she sees but maintaining that we do not see it.
- We can confirm that the place is empty of a dangerous man or empty of danger, while holding on to reality, for example by telling her that we do not see the man or any other dangers or by offering tactile stimulation by stroking her arm or giving her objects to hold and talking about the fact that these objects are real.
- We attempt to refer to her disorder as a 'psychosis', using that sign in an effort to keep her in the real world; for example, 'it is your psychosis that makes you see that man' – see below.
- We can make a drawing with her; when she speaks of 'dangerous', we might try to work with her to draw what she sees/experiences, ask what the man looks like, the colour of his clothes etc., as input for a drawing.
- Activities alone cannot reduce her psychosis; on the contrary. Therefore, we need to lower the pace, avoid

¹ CFD (www.cfd.dk) is a small corporate member of DbI

overloading her with activities, always consider her current state and always have a Plan B handy as well as, ideally, a Plan C.

- The student assistant from CFD, who is a deaf sign language user and studies psychology, is invited to engage in structured conversations with Jane to help us assess her sign language proficiency. These sessions are recorded on video for later review and assessment.
- Jane should receive more praise – she should be praised for who she is, for her contributions to the interaction and for her personality. Thus, rather than telling her that she is good at a particular activity, we can tell her that it is nice to do this activity with her, that it is nice to talk to her and spend time with her, and that she is a lovely young lady.
- Of course, it is also appropriate to praise her for creative things, but in everyday things that she might be less motivated for, we should focus more on the interaction and on her personality.

We may use the following sentences when Jane speaks of the ‘dangerous man’, ‘dangerous’ or other expressions of hallucinations and psychotic states:

- That is what you see. I do not see him.
- It is your psychosis that makes you see the man – I do not see him.
- The place is empty of danger – it is empty of a dangerous man.
- Can you feel me stroking your arm – that is real. You are real, I am real, the man is not real.
- Let us go around the flat together and see that it is empty.
- You see the man; can you tell me what he looks like? Should we make a drawing of him?
- I do not think you are dangerous. You are a lovely young woman, and I like spending time with you.

Sign language assessment

The student assistant began to visit Jane, and we recorded their communication to gather material to assess Jane’s sign language. We chose to involve an outside visitor so that we could observe Jane in a new relationship that would be unaffected by previous conversations or any fixed conversation topics that had already been established.

It took a couple of visits before Jane was open to conversations with the student assistant, but she did not open up to new topics or tell us anything we had not observed previously – she stuck to her rigid repertoire of topics and her repetitive behaviour. Even if the student assistant invited her to take part in games and new activities, Jane’s communication remained fairly simple and lacked any significant development.

In the recordings, there were some exchanges where we were uncertain about how to interpret Jane’s signs – and where, in our eagerness to see new signs appearing in the communication, we may have inadvertently over-interpreted and read meanings into her sign language that she did not intend.

The staff noticed that Jane sometimes carried on monologues where she talked to herself. They were able to capture some of these sequences on video, which made it very clear that these monologues were almost like a self-dialogue. She might lie in bed, speaking about topics we had never previously seen her address, or she might move about – when she was waiting for something – carrying on a self-dialogue that might revolve around familiar topics, but using new signs and a syntax that we had not seen previously.

Method

We have not had a firmly defined or explicit methodological approach to the video recordings, except that the student assistant’s conversations with Jane have concerned activities or routine daily events where the initiative has come from the student assistant with partial support from the educators.

Initially, our focus was on making video recordings to help us form an impression of Jane’s sign language use and her interest in and responses to the conversations.

In our work, we have applied an acknowledging and resource-oriented perspective on Jane’s physical and mental condition and considered her state on the given day and her diurnal rhythm. We have maintained a minimal structure. Thus, although the team has not focused explicitly on methods and theory, apart from the guidelines determined at our team meetings, our approach has relied on methods and theory from KRAP (Cognitive, Resource based and Appreciative Pedagogy) on Bo Hejlskov’s² ideas about non-confrontational educational approaches and low arousal.

Video-based interpretation by interpreters with psychiatric experience

As we started the project, we initially intended to use sign language interpreters in conversations with Jane. However, based on our experiences from Jane’s interactions with the student assistant, we deemed that Jane was not ready for this approach. Instead, we arranged with the CFD’s sign language interpretation service, CFD-Tolkebooking, to have two sign language interpreters with experience from the psychiatric sector conduct video-based interpretation.

We selected clips that showed conversations with the student assistant and the educators on the team as well as clips where Jane talks to herself. It soon became

clear that it was Jane’s self-dialogues that would provide new insights for our professional intervention.

This feedback from the interpreters was a surprise to us, and in Jane’s self-dialogues; they saw many signs that we did not see or failed to notice in our everyday interactions with her. In the minutes from the clinical meeting below, these signs and any interpretations are mentioned.

Summary from clinical meeting – initial evaluation and renewed focus

Intervention until now:

Jane faced severe physical challenges the previous spring and summer, as she was hospitalized in three different hospitals for a period of several months, until she was eventually diagnosed with lupus, for which she is now receiving treatment.

Due to this complication, we were only really able to begin offering an educational intervention in late autumn last year. Her medicine dosage has been reduced, and she is currently taking a low dose of psychoactive medication; this reduction has not led to an increase in her maladaptive behaviour.

In connection with her hospitalization, during which she was bedridden for much of the time, she learned that physical interaction with the staff is not dangerous, and she has recently begun to invite interactions more – not necessarily communicative interactions, but basic physical interactions with the staff in her flat.

Jane is less nervous and restless now and seems calmer overall – although she continues to act out occasionally. Earlier, she would sometimes have a ‘dark look in her eyes’, or she might grind her teeth in reflection of a high level of physical restlessness and insist on immediate gratification.

The educational approach is adapted to match her current state on the given day, which lets Jane experience a higher degree of influence on the activities of the day.

There has been a strong emphasis on empathy and trust and a clear reduction in the demands placed on her. The staff has worked with setting boundaries and giving her instructions, for example, ‘you need to wait; you need to sit here.’ However, these demands are abandoned if Jane becomes very insistent.

The staff has attempted to be acknowledging of Jane’s signals and signs.

Any conversations about Jane’s hallucinations/psychoses now happen on her initiative; in these conversations, the topic of the ‘dangerous man’ recurs over and over again. She asks the staff to check her flat for ‘dangerous’ or ‘dangerous man’ – often followed by her pointing up towards the left (viewed from Jane’s perspective).

Assessment of sign language:

Jane has a fairly nuanced sign language – she uses location, pointing and spelling and has a range of selected signs.

Especially in her conversations with the staff she can be somewhat rigid in her choice of topics, with an emphasis on the ‘dangerous man’, food or requests to go for a drive. She often reverts to these themes, even when the conversation sets out with a different focus.

Whether the sign ‘dangerous’ is the man’s name or an indication that Jane actually perceives him as dangerous is slightly uncertain – her story is that the man grew up with Jane, and that he used to be a boy. However, the staff also encounters different versions of the ‘dangerous man’, featuring different colours, and there is no doubt that Jane is hallucinating. She has also given his name as ‘E’.

Here, her Usher’s syndrome may play a role, as it is known to sometimes cause visual hallucinations; thus, the progression of Jane’s Usher needs to be investigated.

She often uses the sign ‘why’ coupled with an insistent facial expression; thus, her use of ‘why’ may be understood as ‘what now; give me something more!’ Perhaps indicating an invitation/opportunity to engage in a more nuanced exchange about her experiences? However, the ‘why’ sign also appears in a more toned-down version, with calm, almost puzzled facial expression.

Her sign language is more nuanced when she talks to herself and seems to address different topics, situations or maybe even dreams. For example, the interpreters had observed that when Jane lay in her bed with a pillow over her face, she would talk about having a boyfriend and getting married. Perhaps this might offer a possible topic for future conversations with the staff?

The interpreters also saw a story revolving around the notion that Jane could never marry due to ‘heritage’. It would be interesting to learn more about her use of the ‘heritage’ sign – does it refer to religion, God, her disability ...?

She positions herself in relation to turn-taking, acting out different roles in her self-dialogues, while in conversations with the staff she can be more impression-oriented – not passive or inactive, but listening and perceptive without, however, offering anything to drive the conversation forward. Perhaps as a strategy to avoid demands or rejections or to maintain her grip on reality?

Jane is able to negotiate and engage in simple dialogues.

For periods at a time, Jane may opt not to use her vision. When that happens, it is our experience that she

¹ Eng.hejlskov.se

is able to communicate using simple tactile signs, and that the pace in the tactile communication is quite appropriate for Jane. It is easy to fall into a fast pace in conversations with Jane, because she is generally quick in her expressive contributions.

Thus, our initial hypothesis that Jane will be able to develop a more nuanced sign language in her conversations with the staff, which would help us understand her experiences better and make them more concrete, remains a realistic goal.

It is a very typical behaviour for deaf persons with additional disabilities to ‘talk out loud’ with themselves, physically verbalizing their thoughts. However, in some situations, Jane’s display of this behaviour may reflect a deliberate strategy or a skilled coping method in a situation where she waits for something to happen, talking to herself, sometimes even taking on different positions, perhaps as a form of arousal to remain alert while mastering the difficult task of waiting.

Future intervention:

How can we invite Jane into a dialogue where her sign language is just as varied and engaged as it is when she talks to herself?

Can we develop a question technique, a conversation space or a structured conversation format that invites Jane to feel motivated and safe enough to expand her topics of dialogue?

Can this possibly be achieved by the daily teaching staff, or will it require outside professional assistance by a psychologist, who also masters sign language?

The student assistant continues to visit and tries to engage Jane in everyday activities to see whether that might loosen the conversation up.

We are planning conversation strategies for the educators to use when special situations arise, and Jane might open up – or when she is stuck in repetition, strings of words, hallucinations etc.

The sign language interpreters will review additional video recordings of Jane’s ‘monologues’ in order to further uncover her use of sign language. They are doing this together with the deaf employee to make sure that the process includes a sign language user.

We might also try three-person conversations, perhaps in a format where two staff members speak with each other while they are together with Jane and later observe how she reacts to this, and whether it might be a way to invite her into a conversation.

It might also be possible to include more pictures in our communication with Jane.

BUT in all conversations: DON’T FORGET TO FOCUS ON THE PACE! Jane has to be able to keep up, especially when staff members speak with each other in front of her.

Video-based interpretation by interpreters with psychiatric experience – version 2

In August, after the summer holiday, the interpreters met with one of our deaf employees from the team. During this session, they focused especially on a video clip where Jane moves in and out of her self-dialogues alternating with brief dialogues with an educator. The clip illustrates a clear shift in her use of sign language and her choice of topics.

When Janes talks to herself, the process verges on a stream of consciousness where she goes over previous experiences from her life, with a main focus on eating, which plays a big role in her life. When she engages in contact with the educator she expresses a very concrete desire to have some tea. While the educator turns away to make the tea, she resumes her self-dialogue, which she breaks off when the educator returns.

When the educator asks what Jane is talking to herself about, she brushes him off with a single sign, such as ‘tea’ or ‘scram’. It is clear that Jane does not wish to involve the educator in her conversation with herself, something she also demonstrates in another situation as the educator approaches, by putting her hands closer together, thus shrinking her signing space.

It was helpful for the interpreters to involve the deaf employee in the video-based interpretation, as Jane uses several homemade signs and signs that are performed in a way that leaves them open to different interpretations; for example, her sign for ‘out’ has also been interpreted as ‘now’ and ‘God’ in our process.

Thus, the combination of sign language interpreters and a deaf primary contact person proved to be an excellent basis for decoding Jane’s sign language.

The two tracks – status and modification of hypotheses and goals

As mentioned in the project description, our project has involved two tracks: an attempt at **externalization** based on the assessment and synchronization of **sign language**.

That does not mean that our work has distinguished strictly between working with externalization and working to uncover and assess Jane’s sign language and the synchronization of the staff members’ sign language. The two tracks have been interdependent and overlapping, but for clarity’s sake we will try to illustrate them separately in the following:

Externalization

In the early stages of the project, the ‘dangerous man’ played a prominent role in the daily communication between Jane and the staff. Our approach was based on acknowledging Jane’s hallucinations/psychoses, a curious stance aimed at learning more about what she saw and an effort to strengthen her grip on reality by explaining what we see, which also supported our efforts to foster more trusting relationships.

We also sought to lower our demands to her over time and attempt to seize the day or the situation with Jane by adapting the level of arousal to her current physical and psychological state at any given time and to her diurnal rhythm. However, we did maintain a framework of demands, insisting on basic aspects of hygiene, including requiring her to brush her teeth, bathe, wash her hands, toilet routines etc. She has largely been able to meet these demands, with few exceptions.

Later, we also became more aware of her Usher’s syndrome and worked with issues of distance, pace,

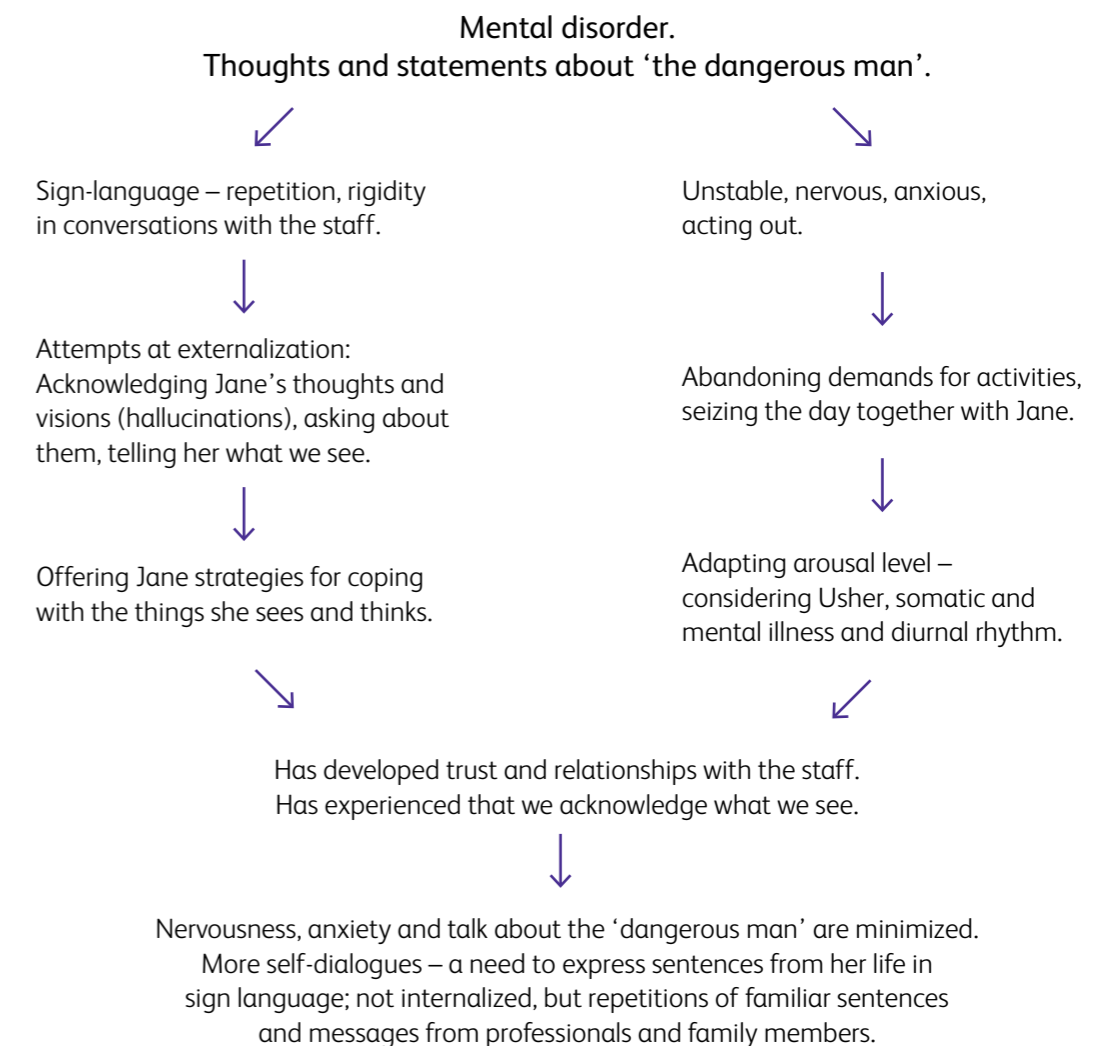
turn-taking etc. The result of this effort gradually became visible after 4–5 months, and by now, in August 2017, the ‘dangerous man’ is much less prominent in her life than before, and on some days he never appears at all.

In parallel with this development, Jane has shown a greater need to talk to herself in self-dialogues where she clearly addresses familiar phrases from her previous life, discussing them with herself, and even takes on multiple roles in the conversation. At first glance, these conversations do not appear to be internalized, but rather reflect the repetition of the language and demands of the outside world.

This raises questions about the psychological matter or phenomenon of the ‘dangerous man’.

Do his appearances represent actual hallucinations or psychotic manifestations, or is he, rather, an invisible psychological companion, who has followed her since childhood or a communicative reaction to feelings of insecurity – or perhaps a combination of several phenomena that have taken on a highly complex form?

EXTERNALIZATION



Sign language assessment

Based on the above, it soon became clear that the synchronization of the staff members' sign language responses to Jane's talk about the 'dangerous man' was having an impact, in combination with the educational approach.

As the 'dangerous man' became increasingly less prominent in Jane's communication with the staff, we saw that she had a clear need to engage in monologues or in self-dialogues where she acted out all the roles.

We cannot be sure whether this inclination towards self-dialogues stemmed directly from a minimization of the presence of the 'dangerous man', but we clearly began to focus more on these self-dialogues or streams of consciousness.

As mentioned earlier, Jane's self-dialogues appear to consist of sentences from her previous life, and although many of them can be related to demands, rejections or corrections from the outside world, they also appear to reflect Jane's underlying hopes or dreams. Many self-dialogues revolved around food, reflecting a basic need, but she also addresses other topics which reflect needs that occupy a higher position

in the needs hierarchy, such as love (the sign for married/marriage), identity and culture (the sign for heritage) and life conditions (the sign for disabled).

Jane clearly does not wish to involve the educators in these self-dialogues; that is apparent in several video clips, which show her switching her language mode from narrative sentences with rich facial expressions in her self-dialogues to questions or instructions with simple or rigid facial expressions in her communication with the educators.

We have yet to crack the code for how to invite Jane into a conversation or, better yet, how Jane might be motivated to invite us into her language universe. However, the way to this goal appears to be paved with the development of trusting relationships and our acknowledgement of Jane's psychological constitution.

Over time, we may thus be able to convince Jane that it is okay to talk to the educators about other topics besides the most basic needs and everyday requests. That would allow us to engage in a shared sociality, generating an interest in the other and creating arenas for both common and private issues that Jane will be able to navigate in.

not be exposed to the big changes but should have time and space to land and consolidate her new mental position and habitual condition.

And today we can see that Jane is very psychologically stable, showing very little hallucinating or psychotic behaviour, and now we can observe that her speech about the dangerous man – which is greatly minimized – can easily be derived or with a simple sign can be ignored.

Our externalization strategies have proven to be long-term, and the stability that has come to Jane's mental life over the last year, means we have now slowly started to work with and develop her social skills – where we will try to involve Jane in other communities, as a social desensitization where she is slowly introduced to interact with people other than her professional partners.

And the sign language is still a fundamental condition in which we have increased the capacity, so that 60% of the staff members are now sign language users.

So the above hypotheses and goals are not forgotten – but the way there, may have become a bit longer. But never mind, as long as the way is exciting, interesting and not least instructive – we will together with Jane find our way!

Thus, our general hypothesis has been partially confirmed – Jane's hallucinations and psychoses have been reduced significantly. We are also convinced that this development has been brought about by the synchronization of our sign language in combination with an acknowledging, relational and non-confrontational approach.

However, we have not achieved our goal of helping Jane to embrace a higher degree of socialization in general. She has achieved a sense of security in her relationships with the regular staff and has thus also shown a higher degree of connectedness with her close contact persons – and thus, with her communication partners – but she has not yet fully invited us into her personal world and psychological reality.

Acting-out behaviour has also been reduced, although there have been severe incidents with direct and targeted physical reactions against staff members; at this point, we have not identified any immediate causes of these incidents.

Thus, despite our doubts, now that we have put down the process on paper and reviewed developments over time, we find that we have achieved real results and are well into what might be called the second phase of the project. In this second phase we propose the following hypotheses and success criteria:

New hypotheses:

- Conversations with a psychologist who specializes in deafblindness and who masters sign language can serve as a catalyst of future invitations into Jane's innermost thoughts, hopes and dreams.
- Structured conversations, prepared ahead of time, can be used to assess the degree to which Jane is able and ready to share previously private experiences.

New goals and success criteria:

- Jane will be able to engage in a dialogue with an external psychologist.
- Jane voluntarily invites staff members into a dialogue about her thoughts – her self-dialogues or streams of consciousness become the objects of a dialogue with a member of staff.

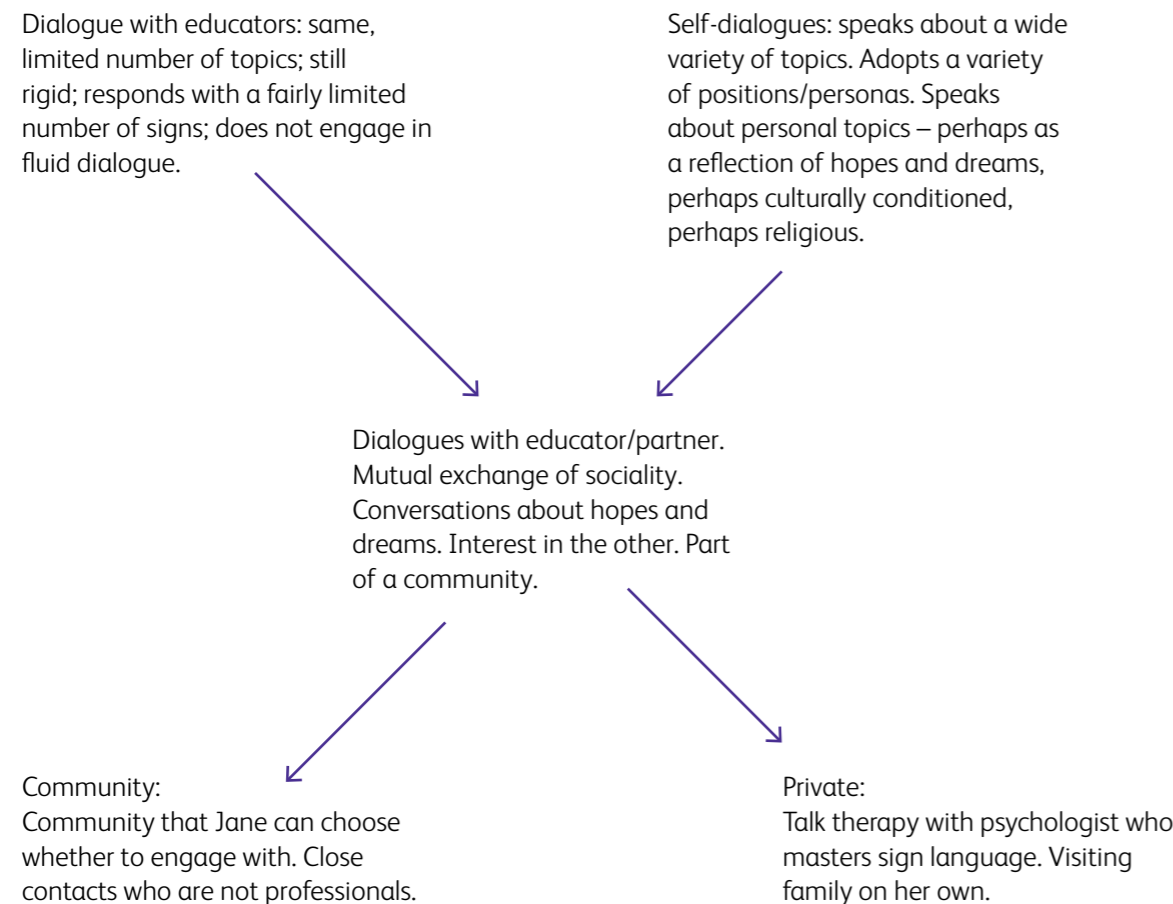
A year after – follow-up and status

September 2018

Here about a year after the new hypotheses and goals were set, we must acknowledge that we have not been successful – at least not in relation to the stated hypotheses and goals.

In the past year, we discussed further intervention in Jane's life, but for various reasons – for this is not just for professional reasons but also for structural reasons – we did agree that Jane should

SIGN LANGUAGE



Ole Wæssner

**For more information, contact:
OLW@CDF.DK**

Debunking the myth that it is never too late to become an effective communicator

Maurice Belote, California Deafblind Services
San Francisco, California, USA

It is critical that all young adults who graduate from educational programs leave school with effective communication systems that include both expressive and receptive modes. I have asserted throughout my career that among the greatest gifts we can give each of the students we serve is a formal, accessible, and well-documented communication system that can be sustained and even expanded throughout life. For individuals who are deafblind, these communication systems are typically multi-modal and include sign language or signed communication, tangible objects, line drawings, photos, voice output devices, etc. Over the past few years, I have become increasingly alarmed at the number of children and young adults who are being denied interventions and equipment to support communication access because these students are deemed to be too old to benefit from communication interventions. These denials are often based on the critical period hypothesis, the idea that there is a limited opportunity or window of time for communication and language instruction, and once this window of time has passed it is no longer possible to acquire language.

The critical period hypothesis contends that there is a critical period, generally believed to be from birth until the age of puberty, for the acquisition of a primary language. The critical period hypothesis was first proposed by Wilder Penfield and Lamar Roberts in their 1959 seminal text *Speech and Brain Mechanisms* and later advanced by the German-American linguist Eric Lenneberg in his 1967 book *Biological Foundations of Language*. Penfield and Roberts (1959) based their hypothesis on a number of observations, including that immigrant children learn new languages faster and without accents compared to their adult counterparts. Penfield and Roberts also observed that when impacted by injury or disease to the dominant cerebral hemisphere, children often speak again within months while adults take much longer and sometimes never recover. Penfield and Roberts also asserted that children reach the peak time for the capacity of

imitation between the ages of 4–8. Many linguists have since proposed the less definite term ‘sensitive period’ to refine the critical period hypothesis; but this word change has not stopped individuals from using the underlying theory to reduce or deny services.

The idea that there is a critical period for acquiring language is being used to reduce or deny speech and language services as well as services of specialists in augmentative and alternative communication. The critical period hypothesis is also being used to deny intervener services because of the belief that transition-age students are beyond the age that such services would be beneficial. In the field of deafblindness, we have decades of anecdotal evidence that this is not the case; many of us have examples of students who did not have breakthrough communication success until late in their educational careers. When I began my teaching career serving young adults of transition-age, several of the students who entered my program did not yet have effective formal communication systems, meaning that they communicated primarily through behaviors (e.g., acting on people and objects, proximity, etc.) and simple gestures (e.g., closing eyes, turning away, etc.) With targeted interventions and consistency, these same students graduated from school with expressive and receptive communication systems that included voice output boards, word lists, graphic schedules, etc. Since that time, I have witnessed countless success stories among students who might have otherwise been regarded as “too old to benefit.”

It is important that educators and family members understand the brain science related to skill development in young adulthood in order to counter the assertion that some young people can no longer benefit from communication instruction simply because of their age. It was once believed that due to maturation of the adolescent brain, students past a certain age no longer had the capacity to learn the skills necessary to become effective communicators. Current brain research suggests that brain maturation and neuroplasticity¹ (the ability of the brain to reorganize

¹ Neuroplasticity: The brain’s ability to reorganize itself by forming new neural connections throughout life. Neuroplasticity allows the neurons (nerve cells) in the brain to compensate for injury and disease and to adjust their activities in response to new situations or to changes in their environment.

“

The good news about brain plasticity is that it may peak in childhood and adolescence but it never entirely stops – at least not until we do. The more you learn, the easier it is to learn the next thing.

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its structure over time) allow for the learning of all skills well beyond childhood, including those skills specific to communication. Furthermore, brain research shows that positive outcomes increase when individuals continue to learn and master new skills throughout their lives. Jensen and Nutt (2015) state, “The good news about brain plasticity is that it may peak in childhood and adolescence but it never entirely stops – at least not until we do. The more you learn, the easier it is to learn the next thing.”

It is also important to differentiate between language and communication because they are sometimes used interchangeably despite their fundamental difference. There are countless definitions of language but common among these definitions is the idea that language provides a structure for communicating words and ideas among a community or group of people. Languages, whether they be oral, visual, or written, have grammatical structures, including syntax, that guide their use, and living languages change and adapt over time to meet the current needs of their users. Communication, on the other hand, is simply the exchange of information between two or more people using spoken or written words, signed communication, symbols, pictures, concrete objects of reference, etc. We strive to ensure that all individuals are provided access to language-rich environments so that they have the opportunity to acquire one or more languages within natural contexts that include competent, responsive communication partners. While acquisition of a primary language should always be the goal, it is not required to communicate effectively and many individuals who are deafblind lead happy, engaged lives regardless of the fact that they did not – or have not yet – acquired formal language.

When asking what can be done to proactively support access to communication and language services at all levels of educational systems, we can focus on the remarkable work of the National Joint Committee for the Communication Needs of Persons with Severe Disabilities (NJC)². The NJC is a consortium that

advocates on behalf of individuals with intellectual disabilities, including those with concomitant sensory needs, and is comprised of representatives from eight organizations: American Association on Intellectual and Developmental Disabilities; American Occupational Therapy Association; American Physical Therapy Association; American Speech-Language-Hearing Association; Association of Assistive Technology Act Programs; Council for Exceptional Children Division for Communicative Disabilities and Deafness; TASH; and United States Society for Augmentative and Alternative Communication.

The National Joint Committee developed the Communication Bill of Rights (Brady et. al., 2016) and representatives from the field of deafblindness were part of the distinguished group of authors, including Dr. Susan Bruce of Boston College. The Communication Bill of Rights includes a total of 15 fundamental rights. A sampling of these 15 rights include the following: 1) the right to request desired objects, actions, events, and people, 2) the right to refuse or reject undesired objects, actions, events, or choices, 3) the right to make choices from meaningful alternatives, 4) the right to be informed about people and events on one’s life, and 5) the right to access interventions and supports that improve communication. The NJC artfully titled their document a bill of rights. For Americans, this has special significance because it is the Bill of Rights of the U.S. Constitution that give us many of our fundamental civic rights. For everyone, the title gives the document special gravitas because rights reflect a moral or principled stance that serves as the foundation for all decision-making and actions. The Communication Bill of Rights can be downloaded at <http://www.asha.org/uploadedfiles/njc-communication-bill-rights.pdf>, shared with families and team members, and posted in classrooms and program offices to demonstrate a commitment to honoring its basic tenets.

In addition to the Communication Bill of Rights, the National Joint Committee (NJC) supports communication interventions and communication

² National Joint Committee for the Communication Needs of Persons with Severe Disabilities (NJC) The purpose of the NJC is to advocate for individuals with significant communication support needs resulting from intellectual disability, that may coexist with autism, sensory and/or motor limitation.

access for individuals of all ages. The NJC’s position paper on Relation of Age to Service Eligibility (2011) states that research has demonstrated the development of communication and language skills into adulthood and that measurable gains are achievable – and likely – when provided with appropriate communication services (cite here). The position paper conclusively states, “Communication is a lifelong activity of value to people of all ages; intervention to facilitate effective communication is warranted for all ages.” This position paper, when paired with the Communication Bill of Rights, provides valuable evidence for families, educators, and individuals who are deafblind when advocating for a strong focus on communication skill development throughout life.

The only critical period that really matters for students who have not had a great deal of communicative success is the one that includes that last few years of these students’ educational careers and the provision of intensive communication instruction to ensure success and positive post-school outcomes. For most individuals who are deafblind, the school years represent the apex of access to communication and language services, and similar interventions in the adult service system will not compare to what was or could have been available during the school years. Maintaining high expectations for all learners, regardless of age and/or the presence of additional disabilities, demonstrates in a very concrete way our belief that all people have the potential to be competent communicators.

This article is based on a workshop of the same title presented at the 2018 DbI Network of the Americas Conference. The author welcomes your comments.



Maurice Belote

For more information contact Maurice Belote:
(mbelote@sfsu.edu)

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Overlaps of autism spectrum disorder and deafblindness: Consequences for the pedagogical work

Mirko Baur

Summary

Autism spectrum disorder (ASD) and sensory impairments are related in a variety of ways – especially in the case of deafblindness. But what does this really mean for pedagogical work? On the basis of evidence research, this article shows on the one hand opportunities for deafblind pedagogy to profit from approaches and practices in the field of ASD – and vice versa. It becomes clear how important it is for people with deafblindness not to be mistakenly labelled with an ASD and at which point special educational differential diagnosis can best begin.

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Why this topic at all?

Firstly, research and reports about people with autism spectrum disorder (ASD) over some twenty years refer to a connection of ASD with special features of perception processing and attention difficulties (cf. e.g. Donnellan, Hill & Leary, 2010; Häussler, 2016; Mesibov, Shea & Schopler, 2005; Rollet & Kastner-Koller, 2018; Schirmer, 2013). Secondly, other research has shown similar connections, such as (a): that the occurrence of ASD appears to correlate positively with hearing impairment, visual impairment and mental disability (cf. e.g. Hoevenaars-van den Boom et al., 2009); (b) ASD appears to occur far more frequently in people with sensory impairment(s) and/or mental disability (cf. e.g. de Vaan et al., 2013); (c). People with the corresponding impairments also show similar to identical behavioural characteristics as people with ASD; the symptoms clearly overlap – especially in the case of deafblindness (Belote & Maier, 2014; Wanka, 2015).

But what does this really mean for pedagogical work? What pedagogical approaches can be recommended in the case of ASD or deafblindness based on this evidence? What could deafblindness pedagogy and similarly ASD pedagogy benefit from this information? What are the possibilities for differential diagnosis of deafblind people with and without ASD? Looking at it from another way, what could it not benefit from?

ASD and suitable pedagogical offerings

In their latest “Community Report on Autism” (2018, p. 6), the Center for Disease Control and Prevention¹ in the USA estimates the incidence of ASD among eight-year-old children at 1:59, an increase of approximately 150% over the estimate published for the year 2000 (cf. Baio, Wiggins, Christensen et al., 2018). Despite a research activity that is strong by special educational standards, many questions remain. Previous studies often show weaknesses and limitations in their design and methodology.

Nevertheless, it has been confirmed for years that behavioural approaches to education are promising (Rollet & Kastner-Koller, 2018, p. 123). This is shown in an overview by the United Health Care Services² (2014, p. 4ff.) of the available clinical evidence on intensive behavioural therapy for intellectual functioning, language-related abilities and constructs, and the acquisition of activities in daily life and social functioning. The evaluation of the relevant literature between 1990 and 2011 by Wong et al. (2014) shows the strongest support for the basic techniques of Applied Behavior Analysis (ABA) among the 27 practices assessed as evidence-based. From another view, Odom et al. (2010) in their evaluation of comprehensive approaches (which integrate different practices) state that their effectiveness is not particularly well documented.

¹ <https://www.cdc.gov>

² www.uhc.com

However, the ABA approach by the Lovaas Institute³ is one of the five approaches that appear to perform best across six tested dimensions of evidence (see loc. cit., p. 427f.). The other four approaches (Early Start Denver Model⁴, LEAP Institute⁵, the May Institute⁶ and PCDI⁷) also use behavioural practices.

The Early Start Denver Model (Rogers et al., 2012) integrates a relationship-focused, development-psychologically founded basic model with behavioural-therapeutic teaching practices including a strong involvement of parents. Even classical ABA manuals (cf. Maurice et al., 1996) have long been oriented towards the usual developmental dimensions, such as motor or social-emotional development, individualising their contributions, taking advantage of the child's interests and relying heavily on the parents' involvement. Accordingly, it is not surprising that in Odom et al. (2010) DIR/Floortime⁸ (cf. Greenspan & Wieder, 2006) appears among the most comprehensive approaches with moderate evidence. DIR (Developmental, Individual-differences, Relationship-based) is a model of human development, with Floortime the core of its application in practice. Both model and application focus on positive emotional relationships as a central development factor. The two basic principles of Floortime are not always easy to reconcile: Following the child's lead and joining the child's world and pull them into a shared world in order to help them master each of their Functional Emotional Developmental Capacities.⁹ The approach thus relies on what is discussed in deafblind education as "harmonious interaction". It is also the basis for a symbolic development that is anchored in relationship, emotional co-regulation and intrinsically motivating experiences.

The best evidence-based recommendation for ASD is using a diverse pedagogy. In an integrative and systemic approach, clear behavioural therapeutic practices are important.

What about evidence in deafblind education?

In childhood, deafblindness is rare in comparison with other disabilities. In Switzerland and other countries, it is often associated with additional impairments and health problems (cf. e.g. Baur, 2015). Not surprisingly, research into evidence-based pedagogical practices is still in its infancy (cf. Ferrell et al., 2014).

The overview by Ferrell et al. (2014) shows that there is evidence for both child-centred approaches and systematic instructional approaches in congenital deafblindness. Tactile learning is central, with additional evidence that research is of urgency, but is generally

highly important. In many aspects, only the first stage (emerging evidence-based practice), can be confirmed in accordance with the evidence standards set by the CEEDAR Centre for Special Needs Education⁹ (see <http://ceedar.education.ufl.edu/wp-content/uploads/2014/08/Evidence-Based-Practices-guide.pdf> [accessed 19.07.2018]).

Sensory perception and communication are recognized as the major and fundamental challenges for children with deafblindness. It is therefore not surprising that there are few if any evidence studies for pedagogical approaches in the classical curricular contents of writing, reading, arithmetic and natural sciences.

According to Ferrell et al. (2014), communication is one of the areas that has been dealt with most in specific research. Here, evidence is available for "child-guided" and "systematic-mediating" approaches, where individualised support should be geared to communication and symbolic development. The tactile communication strategies often practiced (such as touching, use of reference objects or tactile gestures) are already moderately supported. Overall, the authors recommend a highly individualised approach in the field of communication in natural learning environments, integrating the children into every activity and routines combined with many other activities. Indications of the importance of competent communication partners can be found in the section on early education. The evaluation of "literacy" once again confirms the importance of tactile forms of communication and structures such as individually designed daily plans. According to Ferrell et al. (2014), opportunities for a broadly understood "literacy" include offering options or "story boxes" for representation of experiences or stories.

There is strong evidence of "systematic mediation" in daily life activities, combined with learning theory and behavioural practices such as prompting or reinforcement. Behavioural therapeutic interventions have moderate evidence also in challenging behaviour.

With emerging evidence according to Ferrell et al. (2014), an appropriate pedagogical design should feature specialists in deafblindness. Relying on specialists of hearing or visual impairment education is not sufficient, because the effects of deafblindness cannot be equated with the addition of a hearing impairment to a visual impairment. For primary tactile learners, a 1:1 situation may also be required in most learning situations. While individualized support with aids generally seems important, parents of children with cochlear implants confirm comparatively strong evidence for their benefit (Ferrell et al., 2014).

³ www.lovaas.com

⁴ <http://www.esdm.co>

⁵ <https://www.leapinstitute.org>

⁶ <https://mayinstitute.org>

⁷ <https://pcdi.org>

⁸ www.icdl.com/floortime

⁹ <http://ceedar.education.ufl.edu>

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The differences that then become visible are decisive for appropriate pedagogical approaches, for learning, development and participation in the lives of children with particularly great challenges.

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A common pedagogical approach?

Without going further into Ferrell et al. (2014), it can be stated that as with the general overlap of behavioral characteristics between ASD and deafblindness, there is also a common intersection of pedagogical work. It arises precisely because a variety of methods is recommended here and there, which only make an appropriate individually based approach possible. This can only be justified if it is based on the findings of evidence-based approaches and practices and if the individualised support is constantly checked and readjusted in a continuous diagnostic cycle. Close interdisciplinary cooperation along with the active involvement of clients and their relatives are the best way to ensure an optimal fit.

Incidental learning without explicit instruction or intention (Theory of Mind (cf. Frölander et al. 2014) is a very difficult concept for both people with ASD and children with deafblindness. The use of ABA manuals in the context of deafblindness is neither obvious, nor is there any evidence for it. Conversely, pedagogy that is exclusively child-centred or even "child-guided" is not appropriate for children with ASD.

Deafblind education can benefit from structuring practices such as the TEACCH approach¹⁰ (cf. e.g. Häussler, 2016). In view of the more difficult incidental learning, it might also be worthwhile to consider time-intensive early intervention programmes for congenital deafblindness, which would have to meet the specific needs and possibilities in terms of content and pedagogy. Practical work can possibly be further stimulated by sensory strategies in the context of ASD and Sensory Processing Disorder (cf. Laurie, 2014) – strategies for reducing the effects of processing problems in sensory perception.

Conversely, child-guided approaches (cf. Rødbroe, Janssen & Souriau, 2014) would provide basic information on the development of contact, bonding, interaction and communication in ASD. It would be interesting to also examine related ASD approaches such as DIR/Floortime for deafblind education.

Intensive interaction has already occurred in both target groups, which is also related and equally influenced by developmental psychology. It focuses on early interaction and communication skills such as understanding and active participation in interaction routines (see Jefferies, 2009, on the question of the II target groups). This also applies to positive behavioural support aimed at a comprehensively improved quality of life (PBS, cf. Theunissen, 2008): It provides an important basis for possible solutions both for ASD (cf. www.autismspectrum.org.au/pbs) and for deafblindness (cf. www.senses.org.au/positive-behaviour-support), especially if it is communicatively oriented (cf. Carr et al., 2006).

ASD combined with deafblindness

As described above, ASD appears to be more common in people with sensory and/or mental disabilities. It is difficult to make a diagnostic distinction between the different manifestations – especially in the case of multiple disabilities and above all in the case of deafblindness (cf. Hoevenaars-van den Boom et al., 2009, p. 550 & p. 556). It can therefore be assumed that ASD is both overdiagnosed and underdiagnosed (see also de Vaan et al., 2013, p. 492).

This is problematic to the extent that the recommended pedagogical approaches and practices for deafblindness and ASD differ despite common similarities. The pedagogical activity could possibly miss the needs of the client or even be counterproductive (cf. previous chapter and de Vaan et al., 2013, p. 493f.).

A valid and reliable instrument for the diagnosis of ASD in deafblind people is currently not available. However, work has already been done on this (cf. Hoevenaars-van den Boom et al., 2009) on the basis of three ASD assessment instruments and van Dijk's specific diagnostic approach for deafblind children (cf. Nelson, van Dijk et al., 2009). Important differences in the areas of social interaction and communication in ten people with congenital deafblindness between 5 and 28 years of age and a cognitive developmental age

¹⁰ https://www.autism.com/treating_TEACCH

of less than 24 months were found for the diagnosis of ASD. Study participants without ASD performed significantly better in the following categories: openness for contact, reciprocity/joint attention, and communicative signals/functions. Almost significant differences ($0.01 > P > 0.05$) were found in coping with changes and problem-solving strategies. However, the differences were not significant for “stereotyped behavior”, which is often present in congenital deafblindness (see Hoevenaars-van den Boom et al., 2009, p. 555) and exploration and play, where an effect of cognitive impairment is assumed (loc. cit., p. 556).

Similar communication-related indications can be found in an earlier American study (cf. Wanka, 2015), which compared children with CHARGE syndrome with children with ASD. Overall, the study shows “that children with CHARGE are more socially integrated and have better language and communication skills than children with ASD. They are also more involved in sensory-based behaviors such as swing, flutter and turn more [...]” (Wanka, 2015, p. 21).

While work continues on an assessment instrument that can be used, it is worth taking a careful look in practice to: the individual reactions to such things as: shared attention and reciprocity in interaction and communication; contact initiatives in comparison to more instrumental or functionally oriented initiatives of the client; sensory “food” and processing that she or he seeks or shows in her behaviour.

The differences that then become visible are decisive for appropriate pedagogical approaches, for learning, development and participation in the lives of children with particularly great challenges.



Mirko Baur

For more information, contact Mirko Baur:
mirko.baur@tanne.ch

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17th Deafblind International World Conference

GOLD COAST, AUSTRALIA

12–16 August, 2019

Able Australia will host the 17th Deafblind International World conference to be held at the Surfers Paradise Marriott Resort & Spa. Come and join us for an informative and engaging program while enjoying the sun, fun and surf of Australia’s playground, the Gold Coast.

The theme for the conference is
**“Sharing the Knowledge to ACT:
 Accessibility. Communication. Technology.
 Now is your time to ACT!”**

Each day of the conference will feature one of these three themes (ACT).

Accessibility is a quality of life and human rights issue. The accessibility panel will focus on elements that create accessibility for individuals to access the community, educational opportunities, recreation, the environment and positive interactions with family and friends. Speakers include: Christopher Woodfill (Associate ED, HKNC), Isabel Amaral (Consultant/Family Member), Maria Aparecida Nina Cormedi (Consultant) and Namita Jacob (ED, Chetana Trust).

Communication explores how the senses impact communication. The communication panel will focus on receiving and expressing emotions in a tactile way, emotionally intelligent communication, as well as mindfulness and emotional regulation for individuals who are deafblind. Speakers include: Jacqui Martin (COO & Senior Consultant, Langley Group), Heather Lawson (President, Deafblind Australia & Member, Deafblind Victorians) and Linda Hagood (Washington State School for the Blind).

The **Technology** panel will explore the present, adaptations and possibilities of inclusive technology. The audience will be engaged and participate interactively in their session. Speakers include: Anindya Bhattacharyya (Bapin Group), Greg Alchin (Apple Ambassador & Inclusive Design Consultant, Alchin Consulting) and Wayne Hawkins (Disability Policy Advisor, Australian Communications Consumer Action Network). Moderated by Christopher Woodfill.

Of the 208 abstracts received and reviewed, 33 countries were represented and abstracts from 26 countries were accepted. The Scientific Committee was pleased with this geographic distribution, as it ties in with Deafblind International’s strategic priority of Diversity. This diversity in perspectives from across the globe will make for an exciting conference!

Registration is now open at www.dbiaustralia2019.com.au (Early bird registration 01 December 2018 – 28 February 2019)! A rich and engaging program featuring worldwide perspectives on accessibility, communication and technology to empower the deafblind community awaits. Parent and research forums as well as a Global Report on Deafblindness will round out the program as well as provide a variety of perspectives on the conference themes.

Deafblind International’s strategic priority of to Share Knowledge will also come through the Pre-Conference and Network Meetings.

- **Pre-Conference Meetings:** Plan to also attend the pre-conference meetings that feature DbI Networks (CHARGE, Usher, Communication, Youth, Research). Don’t forget to register to attend these sessions as spaces are limited (additional registration costs apply for pre-conference meetings).
- **Network Meetings:** Will be held during the conference program (part of your conference registration fee). Share knowledge and develop valuable partnerships with your international colleagues!

Joins us on the Gold Coast in Australia. Now is your time to ACT!

SHARING THE KNOWLEDGE TO

ACT

ACCESSIBILITY . COMMUNICATION . TECHNOLOGY

“Now is Your Time to ACT”




17th Deafblind International World Conference 2019

AUGUST 12-16, 2019 | GOLD COAST, AUSTRALIA



International Young Researchers Conference on Deafblindness: Generating New Knowledge and Improving Practice

Introductions from Conference organizers

Frank Kat, Vice President DbI and Chair of the Scientific Committee

“Research is to see what everybody else has seen and to think what nobody else has thought.”

— Albert Szent-Gyorgyi

During the 2017 European Conference on Deafblindness, (Denmark), Dmitry Polikanov and I, discussed the current state of research in the field of deafblindness. Our conversations reflected on the critical parameters and attributes for evidence-based systems and practices that address the changing needs of infants, children and adults with deafblindness. It was clear, that there was a need to nurture and support the participation of newly engaged researchers that were adequately prepared to conduct research within this highly specialized field of study. As a result, the idea of hosting a conference focusing on the critical need to attract new and enthusiastic talent to research efforts in the field in deafblindness was born. Therefore, this conference was conceptualized, and plans were initiated to conduct the 1st International Young Researchers Conference on Deafblindness, in Moscow, under the leadership and hospitality of the Deafblind Support Foundation ‘Con-nection’. A Scientific Committee comprised of seasoned researchers in the field was established and supported by the Foundation. Over the past months leading to the conference, the Foundation worked closely with the Scientific Committee to establish a challenging and

interesting program with the theme, “Generating New Knowledge and Improving Practice“. As Dmitry and I discussed over a year ago in Denmark, existing interventions and systems of support must be validated within current educational / support environments and augmented by new research findings. It is only through the collective efforts of an international community that new interventions and understandings can be created. It is our intention to begin to bring together new researchers to systematically approach our current challenges within the field and apply rigorous scientific methodology. In the absence of such evidence, the world’s people with deafblindness will not realize optimal independence and quality of life.

This newly established international event brings together students and young scientists from Europe, Asia, America and Russia who are interested in research initiatives related to deafblindness. I am pleased to report that we have selected 32 participants. These new scientists will present their individual research projects and findings during the course of the conference. They will have the opportunity to share experiences and to create an international network of young scientists, working within an interdisciplinary manner to meet the demands and challenges represented in the field of deafblindness. The program offers the participants enriched



and facilitated opportunities to build their professional network; meet experienced researchers; and engage in plenary lectures from well-known international scholars. In addition, the conference agenda includes opportunities for the participants to deepen their understandings of the experience of living and learning as a deafblind person. This is accomplished through participation in activities that simulate “deafblindness”; listening to the life stories of deafblind adults; and commentary from deafblind children and their parents. In closing, since deafblindness is an extremely low incidence and heterogeneous disability, research and knowledge is often limited. Therefore, this conference is offered as a proactive and significant step to develop and engage the next generation of researchers and practitioners. I look forward to the coming conference and meeting each of you, maybe together we can make a small difference.

Dmitri Polikinov, President of the Deafblind support foundation Con-nection

Our conference is a unique event, to a certain extent. The issues related to deafblindness are normally the matter of concern for practitioners but it does not happen very often that they turn into full-fledged academic studies. This makes this sphere an ambitious field for young researchers and their professional careers, but also creates the need for maintaining the academic traditions, which differ from country to country. The new DBI strategy encourages diversity as a core point of all efforts. This is why it is important for us in Moscow to host not only the representatives of the Russian regions (which are diverse by themselves), but also talented young people from different countries. I hope that our first meeting will turn into a regular event, where we can exchange best practices, learn

about new research methods from distinguished speakers and – what is the most important part of it – elaborate cross-country studies on the problems that unite all of us. Such interaction will be essential to move from practice to theories, i.e. to provide systemic analysis of the deafblind population, its education and social integration across the globe and to develop approaches helpful to people on different continents. The event received support from the Gorchakov Fund as a tool of public diplomacy. It is the first time that the event related to research on people with disabilities received such assistance. In fact, it is indeed public diplomacy, since our common goal is to improve the situation of the people with hearing and vision losses, regardless of borders, politics or cultural gaps. We have many challenges ahead – the evolution



of the deafblind population that drifts into multiple disorders, new technological developments that require specific skills to be integrated into the education and rehabilitation process, changes in the government priorities as far as funding for the science is concerned, etc. However, our international conference should enable the young generations of researchers to face all these issues courageously and to find adequate solutions.

Summary of International Young Researchers Conference on Deafblindness: Generating New Knowledge and Improving Practice

The First International Conference of Young Researchers on the issues of Deafblindness took place in Moscow, Russia, October 9–11, 2018.

The Conference focused on developing the expertise, experience and practices of young scientists and practitioners from various countries studying dual sensory impairment.

The Conference hosted participants from 16 countries: Russia, the USA, the Netherlands, Germany, Norway, Croatia, Serbia, Armenia, Brazil, India, Sweden, the UK, Japan, Australia, Canada, and Switzerland.

This conference can be justly described as a novel event because it offered the students and young

professionals, at the beginning of their career, a unique opportunity to share results of their research with their foreign colleagues, practice working as a team, and offering their ideas for collaborative study projects.

The Scientific Committee of the conference included such prominent professionals and scientists researching deafblindness as Frank Kat (Netherlands), Dr. Saskia Damen (Netherlands), Dr. Jude Nicholas (Norway), Dr. Jerry Petroff (USA), Darja Udovicich (Croatia), and Dr. Alina Khokhlova (Russia).





The Conference included the usual welcoming speeches¹ three plenary sessions², five sub-forums or sections³, and various group activities. Conference participants were treated to a Moscow City Tour on conference opening night and a closing dinner and dancing venue immediately following day 3 of the conference.

Plenary sessions were organized as follows: **Day One:** “What do we study?” dedicated to the discussion of modern trends in deafblindness research; **Day Two:** “How do we study?” focusing on the ways and methods of collecting scientific data; **Day Three:** “How does it work?” dedicated to specific cases of research. Within each session, the best practices from Europe, Russia, and the USA were showcased.

The sub-forums featured reports from students and young professionals on problems of Communication, Education and Mental Development, Movements and Sports, Assisting Adults with Deafblindness, and Family. Reports were presented in two formats – as

workshops or short presentations.

The key element of this Conference was the group work. **Day One** of the event included a team building exercise, containing elements of group training of interpersonal communication. In the course of the exercise, the participants were able to get acquainted with each other and practice solving problems together as a group.

On **Day Two** group work was performed in the “World Café” format, where the participants, divided into groups, collected ideas for research in the realm of deafblindness. Young Russians with deafblindness also participated in the discussion. They told the professionals about themselves, their lives and the things they wanted to share. Their stories and impressions also served as a source of ideas.

On **Day Three** of the event, each group had to present their research project. The various projects included: exploring the feasibility of using technology for independent

living; creating various artistic materials for inclusive education; social integration of deafblind people into the life of their local community; determining the availability of higher education and creating an association of young researchers.

The projects were reviewed by the experienced professionals, members of the Award panel. The best project was awarded to the group whose project was titled: ‘Options for Social Integration of Deafblind People into the Life of their Local Community’.

The members of the winning group were: Elisa Keesen (Germany); Fernanda Cristina Falkoski (Brazil); Lara Gontijo (Brazil); Nikilay Voroshnin (Russia); Martina Celizic (Croatia); Daria Salnikova (Russia). Each of the winners will receive an invitation to the next Conference on Deafblindness in Russia and a four year membership to DbI.

Summary prepared by Dr. Alina Khokhlova (ehalina@yahoo.com)

¹ Welcoming speeches included presentations from the two organizers: Dmitri Polinkanov, President of the Deafblind Support Foundation (Con-nection) and Frank Kat, Vice President of DbI and Chair of the Scientific Committee. Following their presentations, the delegation heard stories from such deafblind adults as Professor of Psychology Alexander Suvorov, Actor and Sportsman Alexey Gorelev and Yulia Kremnena, other of deafblind child

and Head of Program Development of the Regional Offices of the Deafblind Family Association.
² Plenary Day 1: Trends in Research on Deafblindness, moderated by Dr. Jude Nicholas. Speakers included: Dr. Jude Nicholas, Dr. Saskia Damen, Dr. Andrea Wanka, Dr. Jerry Petroff, Dr. Alina Khokhlova and Denis Kuleshev.

³ Sub-forum 1: Communication – Moderator Dr. Saskia Damen
Sub-forum 2: Education and Psychology – Moderator Dr. Alina Khokhlova
Sub-forum 3: Movement and Sports – Moderator Darijai Udovicic
Sub-forum 4: Support for Adults – Moderator Lena Goranson
Sub-forum 5: Family – Moderator Dr. Andrea Wanka



A FEW SELECTED COMMENTS FROM INTERNATIONAL ATTENDEES

Frank Kat As we prepared for the last six months leading up to the conference, I look back now with a smile on my face. It was such a privilege to work with everyone and to see ‘the kids’ perform so well.

We all had our own ideas on this conference, our focus, our aims. If I look back on the conference and the young students, just one word pops up to mind, “Amazing “. New friendships and new contacts were made; new steps in the career of young researchers.

I believe with this program that we touched many of these young people; we motivated them to go on and focus on deafblindness. I am convinced that we will see some of them at the future conferences, bringing great new ideas and results.

Anne Jalakas (Sweden)

Thanks for a great conference and for all the effort that Frank and Dmitri all the rest of you have put into organising this event. It was wonderful to see the young Russian participants grow and gain more confidence over these few days – such a difference from day one to day three!

It was also great to see how much energy was put into this from DbI, trying to ensure that there is a future generation of researchers and competent deafblind workers. I can see on my new facebook-friends how important the conference was for them.

Thanks for making this happen.

Gary Daly (Australia)

As I spoke to many of the participants it was clearly obvious that they got more out of this conference than they thought they would. Their enthusiasm was infectious.

It was fantastic to speak to some of the student participants to see the future through their eyes.

Marianne Riggio (USA)

Thanks, Frank for organizing this conference. I have often worried that this next generation of professionals in this field would not have access to the opportunities that were afforded to many of us to become leaders. I think that events like this will only further inspire them to continue to grow in their work and to be the confident voices who will create new educational and life opportunities for people who are deafblind around the world. So, kudo’s to Frank for your wisdom in pulling this together.

Acquired Deafblindness Network<http://adbn.deafblindinternational.org>**Adapted Physical Activity (APA) Network**

Mads Kopperholdt and Anders Rundt

Emails: mads.kopperholdt@rn.dk;

anmaru@rn.dk)

CHARGE Network

Andrea Wanka

Email: aw@andrea-wanka.de

<http://chargenetwork.deafblindinternational.org>**Communication Network**

Marleen Janssen

Email: h.j.m.janssen@rug.nl

<http://communication.deafblindinternational.org>**European Deafblind Network**

Ricard Lopez Manzano

Email: rlopez@sordoceguera.com

<http://edbn.deafblindinternational.org>**Ibero Latin America Network**

Vula Ikonomidis

Email: vula2004@hotmail.com

<http://iberolatinamerican.deafblindinternational.org>**Network of the Americas**

Marianne Riggio

Email: Marianne.Riggio@Perkins.org

<http://americas.deafblindinternational.org>**Outdoor Network**

Joe Gibson

Email: deafblindoutdoors@gmail.com

<http://outdoornetwork.deafblindinternational.org>**Research Network**

Prof. Walter Wittich

Email: walter.wittich@umontreal.ca

<http://research.deafblindinternational.org>**Rubella Network**

Nigel Turner

Email: nigel.turner@sense.org.uk

<http://rubella.deafblindinternational.org>**Social-Haptic Communication Network**

Dr. Riitta Lahtinen & Russ Palmer

Email: riitta.lahtinen@icloud.com;

rpalmer2@tiscali.co.uk

<http://socialhaptic.deafblindinternational.org>**Tactile Communication Network**

Paul Hart

Email: phart@sensescotland.org.uk

<http://tcn.deafblindinternational.org>**Usher Network**

Emma Boswell

Email: Emma.Boswell@sense.org.uk

Nadja Högner

Email: nadja.hoegner@hu-berlin.de

<http://usher.deafblindinternational.org>**Youth Network**

Simon Allison

Email: simon.allison@sense.org.uk

<http://dbiyn.deafblindinternational.org>

A status report on the “DbI and APA” network

The DbI-APA network, which officially was approved by the DbI family in September 2017, is beginning to be known around the world. APA (Adapted Physical Activity) is getting more and more popular and needed around the world. Movement with the body together, with any learning skills, raise the outcome of what is wanted to be achieved. To move and to be active, as we define APA within the world of deafblindness, is providing the participants to get self-esteem, empowerment and a social dimension, most never have experienced before.

This network, hosted by the two authors, is getting more and more known. By November 2018, members have joined from North- and South America and Europe. With the help of members, with the assistance of the Board of DbI and by the use of the Facebook “Deafblindness & APA”, we all expect a raise in number of members. The Facebook page is where all the members write their information on work, projects and interests. When every member participates in this, everybody can read who the members are and through that, make direct contact, if wanted.

We hope that every member promotes the network at local as well as national and international conferences and in written articles; only for the purpose to create a larger, more dynamic, international forum. We understand the forum as being on the Facebook page; here we ask each other questions when we are in doubt, this is where we seek inspiration, when we need it. This is also where we can coach each other or arrange meetings, when we visit the country of one another; no matter

if you work in the pedagogic field, at University level or as parents; it is all for the benefit of the world of deafblindness.

We like to put forward a very interesting conference within APA. One of our members Mrs. Lauren Liebermann of Brockport University, New York, U.S.A. will host it. It will take place in Scotland, April 2019. www.ssc.education.ed.ac.uk/courses/vi&multi/vconf19.html

We hope to have our first network meeting in 2019. At the time of writing, we do not know the time or place.

Please find the authors through LinkedIn, where we mention the work and writing by us.

If you want to find out more about the network or join the Facebook page please contact: Anders Martin Rundh: anmaru@rn.dk Mads Kopperholdt: mads.kopperholdt@rn.dk

Please go on Facebook: “Deafblindness & APA”



DbI CHARGE Network

Andrea Wanka reports:

A new and larger DbI CHARGE Network is almost here. The last year has been one of transition for our network. The following represents the main developments that have taken place in our network since September 2017.

The CHARGE Network is working on a new project. At the preconference in Australia, we plan to release a little book with stories, inspired by the book of the DbI Youth Network. We plan that the book will have stories from professionals and/or people with CHARGE Syndrome. The stories will give some insights into the specifics of being a professional working with people with CHARGE and from individuals with CHARGE having to deal with the professional.

We are currently collecting short texts of about one page, including photos of the professional and the individual with CHARGE. We are also accepting photos solely of persons with CHARGE. Permissions of photos must accompany all submissions. Our goal is to have the book completed prior to the world conference in Australia. There will be a digital version and printed booklets. Perhaps we will find somebody who will support us financially to publish the printed versions.

During the last years we have tried to find other words for the letters of the acronym CHARGE. Words, which also provide insights in the phenotype of CHARGE, but in a positive way. Words, which would fit and describe people with CHARGE Syndrome, like the letter “c” of the acronym not just meaning “coloboma” but “charming” or the letter “h” not just meaning “hear” but also “humor”. Perhaps we could add some pages with these other meanings for CHARGE, too. But we have not decided on this topic, yet.

In addition, we are also working through our website, attempting to make it up to date and also a bit more attractive. Therefore, we are looking for new pictures (with permission of those photographed). If anyone wishes to share some photos, please send them to me.



Andrea Wanka

Best from CHARGE Network
Andrea Wanka
(wanka@ph-heidelberg.de)

“The CHARGE Network is working on a new project. At the preconference in Australia, we plan to release a little book with stories, inspired by the book of the DbI Youth Network.”

Communication Network

Marleen Janssen reports:

We are expanding our organization team of the Communication Network with a few members from abroad. This will help support the smaller communication network more effectively. The website link for the DbI website is still in the developmental stage. We are happy to announce that we have now launched our DbI communication network Facebook group. There are already people who joined this Facebook group, but more participants are welcome. If you are interested in communication and deafblindness please visit www.facebook.com/groups/156113075090218/about/ and join us. If you are a group member you can also post information that you think would be interesting to share.

Reports from Smaller Network Groups

Report on annual seminar of Masters of Deafblindness alumni by Saskia Damen

On September 26 the annual alumni seminar of the master Communication and Deafblindness was held at the University of Groningen. The topic of the seminar was 'Moving Together – co-creating meaning within the bodily-tactile modality'. The first speaker was Dr. Marja Cantell, who is an assistant professor specialized in research on movement in individuals with special needs. Her presentation, titled 'Meaning in movement: interaction in motion', focused on movement analysis. She showed examples through video to explain how movement qualities can be observed. Dr. Cantell described the psychological aspects of movement and the influence movements can have in social interactions.

The second presentation was given by Itay Yatuv from Hakvutza Dance School, Israel. His talk concerned the use of contact improvisation and the role of partner competencies. Itay showed video-clips in which he used movement to interact with a toddler and with a person with deafblindness. The presentation revealed that moving together can create shared understandings and mutual trust. After the lunch, participants practiced with contact improvisation in a workshop held by Itay Yatuv. The overall impression after the seminar is that a focus on movement is a relevant perspective for research on communication of people with deafblindness and can also provide relevant input for interventions.

Report on Masters of Communication and Deafblindness Network by Marleen Janssen

On September 26, 2018 seven students of the Master Communication and Deafblindness graduated at the University in Groningen, Department Special Needs Education and Youth Care. Here follows an overview of the graduated master students and their topics. If you are interested in a thesis you can contact me or you can contact the authors yourself. We try to support the authors to give more information on the facebook page and publish an article in the Journal of Deafblind studies on Communication

- Graham Nolan (UK): Using Mindfulness and Self-Massage techniques to improve the quality of tactile interactions with partners who are congenitally deafblind
- Christine Oskamp-Maas (the Netherlands): Assigning meaning to tactilely observable images and symbols. A case study.

“
... a focus on movement is a relevant perspective for research on communication of people with deafblindness and can also provide relevant input for interventions.
”

“
We have four students from Africa, and one each from Canada, the UK, Norway and the Netherlands.
”

- Gro-Anita Nummedal (Norway): Identifying cognitive strategies within the bodily tactile modality through social interaction between a person with congenital deafblindness and a partner
- Wija van der Kaaden-Huttinga (the Netherlands): I support you in your loss. Evaluation of an approach to coach caregivers in their support in the loss of a beloved one.
- Johanne Godo (Norway): A communicative encounter between a fluent signer and a youngster with CDB. What tools can be used to describe spatial elements?
- Ismael Byaruhanga Kus (DR Congo): Analysis of social construction of congenital deafblindness in relation to education in East and Central Africa.
- Camilla Foote (Norway): Access to cultural language out of the ordinary. A trans-languaging perspective on conversations with a child with congenital deafblindness.

In this new academic year 2018–2019 nine students are doing their masters. They are required to write their research proposal and their thesis more in line with other international master tracks at the University of Groningen which means a bit more pressure and deadlines; but all in all, this should ensure better results in their articles. These students are supervised by Jacques Souriau, Anne Nafstad, Marlene Daelman and Paul Hart mainly on the content of their theses; and by Saskia Damen and I in the academic writing.

We have interesting topics again this year on which we shall report in the next issue of DbI Review. We have four students from Africa, and one each from Canada, the UK, Norway and the Netherlands.

If new students wish to apply for this master track in Pedagogical Sciences Communication and Deafblindness for the academic year 2019–2020, they can contact the academic advisor at the University of Groningen, Alette Arendshorst: (A.M.Arendshorst@rug.nl) or Saskia Damen (S.Damen@rug.nl) or Marleen Janssen (h.j.m.janssen@rug.nl).

Concrete Activities of the Main Network

DbI Review Book on Communication: overview of 40 years

In Aalborg we decided to fulfill a wish of the DbI Board to make a book of all interesting articles about Communication published in the DbI Review for the last forty years. We are in the starting phase to get access to all these articles. If you have good suggestions for interesting articles, please let me know.

Preconference Australia

On Saturday August 11, 2019 we will organize a preconference at the conference in Australia with the theme: Video analysis and Video feedback in Communication. If you wish to join this preconference you can apply by contacting Marleen.. If you have ideas for a contribution, you can let me know. We have already some contributions from Japan and the Netherlands; more ideas are very welcome.

Network meeting Australia

On Wednesday August 14, 2019 in the afternoon we are planning a meeting of the Communication Network. We do not know the details yet, but the main goal is, to have a presentation on video analysis of communication and after that to discuss good ideas for: a) expanding the members of the Network, b) plan concrete meetings with concrete themes, and c) how to use social media better to share knowledge around the globe.



Marleen Janssen

For more information contact Marleen Janssen, on behalf of the DbI Communication Network Team: h.j.m.janssen@rug.nl.

The Creative Arts Network is a new network of Deafblind International

This Network hopes to achieve recognition of Arts and arts therapies as a useful modality in working with individuals with deafblindness and to promote the creative rights of all individuals, including those with deafblindness. Through working together to connect and raise awareness of artists and therapists working with individuals with deafblindness, this new network aims to improve the quality of creative services for deafblind people.

The founding members of the network are chair Emily Walters (Australia), Jennifer Bollet (USA) and Daniella Forchetti (Brazil) who share a brief profile as follows:



EMILY WALTERS is the Creative Arts Therapist Coordinator at Able Australia¹. Emily facilitates the Able Art program which provides art therapy programs to people who are Deafblind in the form of groups and one on one sessions. Emily enjoys guiding individuals who are Deafblind to create works that they can enjoy through art-making and through engaging in different ways with the finished product. In December Emily will support Deafblind people to put their annual Able Art Exhibition in the Melbourne CBD where work will be admired by thousands of passers-by. More information about this program can be found at: www.ableaustralia.org.au/what-we-do/improved-health-wellbeing



JENNIFER BOLLET is the Creative Arts Teacher for Deaf-Blind Youths and Adults at the Helen Keller National Center in Sands Point, New York. Jennifer works proudly in the Creative Arts Department in a position previously held by her mother, saying that “helping deafblind individuals be creative and showing them that art is an option for them is such an eye-opening experience. When they realize that they can still be creative and make a multitude of things that are tactile they feel proud of themselves and confident.” More information on this program can be found at www.helenkeller.org/hknc/creative-arts



DANIELLA FORCHETTI is an Artist-Researcher, Audio-descriptor and Speech-Language Pathologist. She is the director and Interpreter of the DiDanda Experimental Group of Dance under the Accessible Art and Educational and Inclusive Dance program in Brazil. Recently the DiDanda Group won the 1st Art and Inclusion Award of the State Secretariat of São Paulo – Dance category / 2018. In August and September Daniella is giving the introductory course to the Audio-description in the Performing Arts, in partnership with SESC Consolação, offered free to 20 participants. More information on Daniella’s programs can be found at: www.daniellaforchetti.blogspot.com.br www.artedainclusao.blogspot.com.br www.linkedin.com/pub/daniella-forchetti/36/779/974

Individuals who are interested in learning more about this new network or joining are encouraged to contact the network chair: Emily.Walters@ableaustralia.org.au

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

DbI Outdoor Network

Joe Gibson reports:

The outdoor network continues to grow! There is currently 145 people from 21 different countries on our e-mail mailing list and 168 people in the Facebook group. Do you want to find out more about different ways to use the outdoors or share your outdoor events, ideas or research? Then join the outdoor network mailing list or Facebook page with others who have an interest in this area. You can join the mailing list by sending an e-mail request to Joe.Gibson@deafblindoutdoors@gmail.com or join the Facebook group which can be found on Facebook by searching for “Outdoor Network, Deafblind International”. The outdoor network has recently had its annual outdoor week in Norway and below is a report from that week.



Joe Gibson

For more information, contact Joe Gibson at deafblindoutdoors@gmail.com

Outdoor Network Outdoor Week, 17–21, September 2018

By midnight on Monday the 17th of September all the participants (19 deafblind people and 47 in total) from five different countries had arrived at Johnsgård in Sømådal, Norway (www.johnsgard.no). On Tuesday morning despite the long day of travelling by plane, train, minibus or cars, some of the participants were up early to collect fishing nets put out the night before.

At 11:00 we had an “official” welcome and introduction and everyone got a sitting mat and wooden mug to use for the week. Then, after some getting to know-you-games, we began working. There were five different work stations: cutting and chopping wood for the fire; making flatbread; making butter and cheese; cleaning the fish we had collected; and laying out the nets to collect more fish. Everyone had the opportunity to try all the activities as well as to

explore the beautiful scenery and autumn colours around Johnsgård.

On Wednesday morning everyone met each other and received a “mapstick” to help find their way to Jotsætra, the summer farm in the mountains that was the destination for today’s trip. The group split up naturally and the long walk gave the opportunity for many different conversations as well as the chance to see Johnsgård from a different angle. When we got back there was more work to be done to prepare dinner. More fish had to be cleaned and prepared for grilling or smoking, and vegetables to pick, clean and cut. After dinner there was a party with singing, drumming, guitars and even a tuba!

Thursday morning saw us set off for a longer trip but over slightly easier ground. There was a quiz along the way. Waffles and pancakes had been cooked over the fire to meet us when we arrived. The destination today was “Bua Mi” a small cabin built by two

young deafblind men. On the way back there was the option to either take a more scenic route through the forest or get a ride in a car!

In the afternoon before dinner there was a guided tour of the “nature sculpture park” which has been built by deafblind people in collaboration with professional artists for over the last 20 years. That evening we enjoyed another fantastic dinner from the outdoor grill to finish off a great week.

Early the next morning everyone began the long process of travelling home. The quote of the week from one of the support staff during the last evening was: “that the outdoor network week has been great, like a warm bath.” Our thanks go to our hosts this year at Johnsgård Tourist centre and the organiser Reidar Martin Steigen.

In 2019 the plan is to hold the outdoor week in The Netherlands; more details will follow soon!



Making flatbread



Butter and flatbread made by the participants



Tactile symbol linked to the map stick

Research Network

Walter Wittich reports:

The DbI Research Network is well into its fourth year of existence, and we continue to grow and expand. As of November 2018, we now have 111 members on our e-mail contact list.

Saskia Damen and Flemming Ask Larsen continue maintaining the Deafblind International Research Network Facebook Group, which currently has 219 members and growing. Come look us up and join in the conversation! **Christine Lehane** continues to maintain our Deafblind International Research Network LinkedIn group, which currently has 68 members.

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.

The **1st International Young Researchers Conference on Deafblindness** just recently concluded in October in Moscow, Russia. You can catch up with some of the events and testimonials on the Facebook page of Deafblind International where the conference organizers have provided a 6 min video with details of the event.

The review of research abstracts for the next DbI International Conference in **Gold Coast, Australia, in August of 2019**, has been concluded and I am excited to report that both the number and the quality of submissions outrank our previous conference years. This promises a strong and exciting program for the coming event.

The network pre-conference workshops will include speakers from Canada, the USA, Sweden and Australia, covering topics ranging from demystifying research methods, participation opportunities, guidelines for bringing research into practice, as well as dissemination techniques and the use of social media for research.

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The review of research abstracts for the next DbI International Conference in Gold Coast, Australia, in August of 2019, has been concluded and I am excited to report that both the number and the quality of submissions outrank our previous conference years.

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The research components within the main conference will include 2 sessions with multiple short (15 min) traditional research presentations, a research networking session as well as an extensive poster session that will allow us to discuss current research developments, ongoing studies, relevant findings and share new ideas.

We look forward to seeing you all in Australia! Until then, if you have any ideas for us, or other requests for research-specific information, we look forward to hearing from you, and please feel free to check out the networking opportunities on our web page and contact us with your interests and thoughts.



Walter Wittich

Walter Wittich representing your
DbI Research Network Team.
For additional information contact:
Walter.wittich@umontreal.ca

Usher Network News

Emma Boswell reports:

We are very excited to be in the midst of organising for the upcoming Usher Network Pre-conference, being held on 11th and 12th August 2019, Surfers Paradise, Gold Coast, Australia.

It has been an extremely busy summer getting things prepared for the event; there's still a lot to do! The committee members have been working tirelessly selecting speakers, raising funds for communication for our members and reaching out to people with Usher around the world to promote this special conference.

Please come along and join us, before the main DbI extravaganza at our intimate and informal pre-conference focusing on all things Usher. If you would like to be a speaker, want a specific topic covered or would just like to share your views you are very welcome. Please do contact the Usher Network chair: emma.boswell@sense.org.uk. We would love to have representatives from as many countries and continents as possible joining us.

The programme will be coming together in the next few months. Please see our DbI Usher Network webpage (usher.deafblindinternational.org) for more information and updates.



Emma Boswell

Emma Boswell, Chair, Usher Network
emma.boswell@sense.org.uk

With regards to communication, we want to make sure that we provide communication support for all who need it including interpreters and palantypists. We need a significant amount of time to make sure we have sufficient numbers to cover the required need. There is no central budget for this, so if you know of any organisation or company who may be happy to support us by funding part of the communication costs, or sponsor individuals to attend please do let us know. This would be a great boost to our members and we hope as many people with Usher as possible can attend the pre-conference. We want the event to be inclusive and engaging. Please contact me if you have any suggestions or contacts.

DbI Pre-conference on Usher Syndrome

Gold Coast, Australia / 11th–12th August 2019

- Are you keen to learn more about Usher syndrome?
- Do you want to share your professional experiences in this field?
- Do you want to learn more from people with Usher, about their own personal experiences, challenges and achievements?

If yes, then join us at the International Pre-Conference for a fascinating programme of Usher events covering; psychology, employment and social fields, as well as an 'expert panel'. There will be speakers from all over the world, together with people from all areas of the Usher community, including professionals, Usher people & their families. Throughout the two days, there will be tea and coffee and a buffet lunch.



Deafblind
International DbI

SHARING THE KNOWLEDGE TO
ACT
ACCESSIBILITY . COMMUNICATION . TECHNOLOGY
"Now is Your Time to ACT"

If you would like to be a speaker or be added to the mailing list, please contact: emma.boswell@sense.org.uk
For more information on the conference please go to: <http://usherdeafblindinternational.org>

Usher Conference in Germany

International Symposium on Usher Syndrome USH 2018

July 19–21, 2018 in Mainz, Germany

I have recently returned from the USH2018 conference, which was held over three days in Mainz, Germany. It was the 4th international symposium including a two day scientific programme; aimed at gathering researchers, scientists, academics and professionals in the Usher medical field and a one day ‘patient’ day; inviting those with Usher and their families to come together to discover the latest findings, as well as network with one another.

The area of genetic and scientific research is always an exciting one in the Usher world. There is a lot of exciting and potential developments and trials going on all over the world. It was an interesting mix of those looking for a cure and those wanting a cure collaborating in the stylish backdrop of the Atrium Hotel and Conference Centre, Mainz.

The first two days were heavy going, with lots of medical jargon which at times was difficult to follow especially for a layperson like myself. Over the two scientific days, there were 30 speakers sharing the latest discoveries from labs and universities all over the world. It was the first time most of this information was being shared, especially on an international platform, so much of the data was protected by copyright and not for general publication. Therefore as a delegate there was a real sense of privilege and advantage of being lucky enough to be there to share in Usher trade secrets!

Whatever people’s views on the subject; most scientific research involves animal testing of some sort, and Usher research is no exception. Many of the presentations included clips of this research so it wasn’t for the faint hearted. One of the most powerful memories included watching a video clip comparing an animal with normal sight and the same species of animal injected with an altered Usher gene to show how their mobility / behaviour is affected. Each animal selected (pigs, monkeys, mice, zebra fish) are chosen because of the close genetic similarity to humans or for efficacy reasons. Some of the information sounded both scary and made me feel a little squeamish, especially imagining these tests being translated into human batteries. I sat constantly wondering how it would work in my ‘own’ eyes. A lot of focus was placed on exciting breakthroughs with zebra fish models, gene sequencing, hair cell models and gene splicing.

Some of the information was more straightforward than others. One of the most marvellous things for me was to observe the scientists converse with one another over the question and answer sessions. They understood

each other’s jargon perfectly – I can only liken it to how people that can’t sign feel when they watch two BSL users deep in conversation IE mind boggling!

I relied on two interpreters throughout the conference which intrigued a lot of the medical professionals and academic scientists, and proved quite an ice breaker during breaks and lunches as they were interested by my support needs as a ‘real’ life study! Asking how the interpreters were coping with the heavy jargon (just so you know – with great difficulty..!). Interestingly, the first day I took in a lot of new scientific information, then by the second day I began to understand some of the techniques and models because some of the medical teams from all over the world were doing similar research or using similar techniques and experiments. So the slight overlaps meant it was a chance to learn what the previous day had been about!

The only downside was some speakers were speaking very fast, with heavy accents and the venue was a darkened room which can be a challenge for people with Usher. There was also a distinct lack of eye breaks, but there was so much to get through I can understand this would have been somewhat disruptive to a very full programme.

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It was a rare opportunity for the medical professionals from all over the world to meet the ‘patients’ they were in theory, treating. About 200 people attended, as well as 100 people live streaming.
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Rebecca Alexander is an author, psychotherapist, group fitness instructor, advocate, and extreme athlete who is almost completely blind and deaf. Born and raised in the San Francisco Bay Area, she currently lives in New York City, and her speech was awe inspiring.

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At the end of the scientific programme there was a boat trip around the beautiful city, Mainz. This marked the end of the scientific agenda and a focus on the ‘patient’ so people with Usher and their families started to arrive and register. It was a rare opportunity for the medical professionals from all over the world to meet the ‘patients’ they were in theory, treating. About 200 people attended, as well as 100 people live streaming. The atmosphere became slightly more lively and the environment immediately changed, with more people and the stalls had different displays. The most powerful were large posters of portrait photos and a bio about each person with Usher and their achievements and quotes from them. The photographer responsible set up a studio at the conference and was asking for volunteers to add to the display. I was happy to oblige – I just hope she got my best side! Downstairs in the main hall the lights had been changed, and were switched on throughout the day which was more accessible. I was not keen on the word – patient (!) but definitely more keen on the content – a patient’s view of Usher.

Mark Dunning, from the Usher Coalition, the organising institution, opened both the scientific and patient days with wonderful plenaries. Talking about family life with his daughter, who has type 1. A girl after my own heart, as the audience learnt of her experience doing Camp America, the very same thing I did, all of twenty years ago! During his plenary for the patient day he spoke about his recent exposure to being in a foreign land and not always understanding what was going on around him. Mark had recently experienced language barriers between English and French and expressed his frustration at not being able to join in with his colleagues fully in conversations. An experience he claimed had made him feel closer to Bella, his daughter, because of her language barriers on a daily basis. Lip reading and having a lack of access to information. I thought it was a lovely metaphor and also helped those without a scientific background relax at the thought of not understanding everything completely!

There were so many highlights from the patient day. World renowned Rebecca Alexander who has written a best-selling book entitled ‘Not Fade Away: A Memoir of Senses Lost and Found’ gave a motivational plenary. Rebecca Alexander is an author, psychotherapist, group fitness instructor, advocate, and extreme athlete who is almost completely blind and deaf. Born and raised in the San Francisco Bay Area, she currently lives in New York City, and her speech was awe inspiring. During the coffee break, I met some deaf / deafblind people from all over the world and using international sign language (which is different from BSL) I managed to have fully fledged conversations about Sense, life with Usher in the UK, even the weather! I remembered a bit of American Sign Language from my time at Camp America which came in very handy. While it was good to talk to different people from all over the world it was also good to meet several people with Usher from the UK, some old faces and some new.

Julia Moser, Vienna, AT gave the most heartfelt personal account about her life with Usher and how she now works in Law, is married with a family despite an earth shattering (and mis)diagnosis.

Towards the end, there was a Podium discussion with patients, scientists, clinicians and professionals, moderated by Mark Dunning. The guests were Laura Bingenheimer, Isabelle Audo, Brendan Creemer, Claes Möller, Uwe Wolfrum and yep you’ve guessed it – me!

It was hard being on the panel, not knowing what questions would come up or the context. No one likes to be on the spot! It was extremely difficult to strike a balance between my professional and personal perspectives without any conflicts, but it was interesting to experience being ‘live’.

Claes Möller closed the symposium with probably my favourite plenary. Claes is well known in Usher circles he has been working as an Otolaryngologist for 29 years and as otologist and audiological physician for 14 years. From 1996 he has been a professor in Audiology and currently works at Örebro University. His presentation

on 'The Urgency of Interdisciplinary Healthcare and Support for People with Usher syndrome' was a plea for people to work together for the good of the Usher patient. But it was his closing quote that resonated the most with me 'my dream is to get children with Usher syndrome to learn sign language because if the cochlear implant fails or their sight deteriorates, they suddenly can't communicate because they do not know how to use sign language.' I am very pleased to hear such a prominent medical professional saying this as part of my professional work has been with children undergoing CIs and all have been advised to stop using sign language by the medical professionals treating them.

At the end of the final day, everyone joined in for a 'family' dinner. The networking was excellent and informative and I spoke to families from Australia, Germany and Austria, including a couple whose 2 year old daughter had just been diagnosed.

For people with Usher who want to share and learn about Usher and meet people from different places I would highly recommend attending the Patient Day. All in all it was a wonderful experience for me, and empowering to see people with Usher learning more about their condition and what support is out there for them. There will be a full transcript of the patient day for any of you are interested, it will be released by the end of this month. Please see: International Symposium on Usher Syndrome – USH2018: <https://ush2018.org/en> for more information on the speakers, topics and transcript.

Emma Boswell,
National Usher Co-ordinator
Usher service

Obituary of Professor Maria Bitner-Glindzicz

Professor Maria Bitner-Glindzicz, geneticist, was born on June 26, 1963. She died, shortly after colliding with a taxi while cycling in London, on September 20, 2018, aged 55.

Here at the Sense Usher Service, UK, were deeply shocked and saddened to learn of the tragic death of Professor Maria Bitner-Glindzicz. Her specialism was Usher syndrome and she was a well-known and hugely respected contributor to the Usher Community. She was a clinician and scientist and she undertook a great deal of amazing work in the field of Usher, including helping to set up the dual sensory clinic, which ran until 2017. She spoke at DbI Usher Network Pre-conferences, wrote articles for Talking Sense magazine and DbI Reviews, not to mention the excellent networking she did with families, and people with Usher themselves. She took an interest in everyone that she met and would always take the time to answer questions and explain things to people in a way they could understand.

Bitner-Glindzicz was one of the first clinicians to become involved in the 100,000 Genomes Project, to sequence the first human genome, and thanks to Maria and her colleagues it was possible to map out a person's genes in a matter of hours following years of extensive research. This was absolutely groundbreaking information for people with Usher and their families. She will be sorely missed by the Usher Service and everyone that knew her. Our thoughts are with her friends and family at this tragic time.

Emma Boswell, National Usher Co-ordinator, Usher service, Sense UK and Chair of DbI Usher Network (emma.boswell@sense.org.uk).

“ She was a clinician and scientist and she undertook a great deal of amazing work in the field of Usher... ”

World Record 'Largest Tactile Signing Lesson'

Sense and Mazars make it into the Record Books!

It is with great pleasure that we are able to announce that The Guinness World Records have recognised us for holding the world's 'Largest Tactile Signing Lesson'!

In October 2018, members of the public joined staff from Sense and our partner, international accountancy firm Mazars¹, outside the famous Tower of London. They were there to participate in the event to raise awareness of the different communication methods used by people with complex disabilities.

The 30-minute lesson, led by Emma Boswell who has Usher syndrome, focused on one form of tactile signing – 'deafblind manual', an adapted form of finger

spelling taken from British Sign Language (BSL). 390 participants were recorded on the day, exceeding the target of 250 people required to achieve the record.

This was one of a series of events, which took place during that week, to raise awareness and vital funds for Sense. With the record now verified, it is anticipated that it will be included in the next Guinness World Records annual book. A certificate has been delivered to Sense and we hope to frame and display this at the Sense head office.

For more information, please see Sense Twitter (www.twitter.com/sensecharitystatus/1057233433448058880) and Sense Usher service Facebook (www.facebook.com/sensecharity).

Radio BBC4 – Tactile Signing Interview

In case you missed it, Emma Boswell was interviewed about the event, and about hands-on communication, on BBC Radio 4's 'In Touch' programme. You can listen again and read the interview transcript at www.bbc.co.uk/programmes/m0000mkg (scroll down the page for the transcript).

IN TOUCH PROGRAMME, BBC Radio 4; 2nd October 2018

Peter:

Good evening, tonight the MP who wants greater protection in the law against discrimination to guide dog owners and the marathon designed to give greater understanding about Deafblindness and a place in the Guinness Book of Records...

And the charity Sense is also looking for more understanding but it has gone about things in a rather different way.

Sense represents people with the dual disabilities of sight and hearing loss and in London earlier today they mounted an attempt at a world record, the idea

being the biggest ever half hour lesson in how many Deafblind people communicate, Emma Boswell who is Deafblind herself is leading the singing marathon she has Usher Syndrome one of the frequent causes of the dual disability. Well, before the event and using tactile signing, with her male interpreter, she explained how people communicate using touch...

Emma:

The first and main method is Deafblind manual, which is 26 hand movements signifying the alphabet and being able to spell 'communications' onto someone's

¹ www.mazars.co.uk



Emma Boswell (centre) during BBC interview

hand'. There are other types of tactile communication as well including hands-on sign language, whereby the Deafblind person traces the communicators hands using BSL (British Sign Language) then the other thing to mention Peter is something called tadoma, which is where a Deafblind person will follow communications by putting their hand on the throat and neck of someone as they are speaking and that's following the vibrations caused by speech.

Peter:

Tell me some more about that, what actually can you tell from throat vibrations, how does that work? Can that give you precise words? Just give us a sense of what's going to happen at the marathon and what are you trying to achieve?

Emma:

Well, with 250 people there, hopefully a lot of learning that's for sure! I am hoping to be part of a world record and a first attempt which is going to be a big achievement, but really this is about awareness, awareness for Deafblind people and awareness for people who might not even know how to communicate with someone who is Deafblind or might be bit anxious about touch communication. I am sure many people have done that thing in the train station or at a bus stop, seen someone blind or Deafblind and not had the confidence to approach them, but today I hope we can

achieve some really good awareness and the event is more than just a Guinness World Record.

Peter:

Has technology come up with any alternatives to manual signing?

Emma:

Well, I would say that some technology is very helpful to people who are Deafblind, but not everybody uses the same type of technology, iPads are brilliant providing somebody can see enough... There is another side to this and we know that the world is forever changing and people are becoming more reliant upon technology as time goes by, sadly some people will be left behind because technology is inaccessible. In terms of manual communication, there is nothing like the human touch and having a person to communicate with you.

Peter:

Have you had situations where you have been surprised where someone really did know the Deafblind manual and could communicate when you wouldn't have expected it?

Emma:

Do you know what, yes, this happened quite recently to me, I went to do a school visit and a little girl came up to me and said 'I can do that' and she could

communicate with me absolutely fantastically! She was as thrilled as I was because she could reach out and communicate with me and it was incredibly impressive that she had the confidence to communicate – she can't have been more than about 11 or 12 years old. It is brilliant when people come up to you and communicate with you, it is wonderful because all communication is good!

Emma:

What makes a really good interpreter is someone who asks the client 'what do you want from me? What do you want me to do to help communications be the best they possibly can be?' SO, it's all about attitude first of all. What I find frustrating is when communications breakdown because, I have lost my part in the conversation and I can't follow. An interpreter is an important go-between and somebody who is very helpful to make communications truly work.

Peter:

Do you think you're going to hit your 250?

Emma:

My fingers are crossed tight and even though I am doing sign language at the moment I am keeping my legs crossed instead! But this is a truly unique occasion Peter and a wonderful opportunity for people to learn and spread some awareness and stop Deafblind people from becoming isolated it is a real opportunity in the making so I don't think you can put a price on that!

Emma:

Good morning, this is Emma Boswell here at the event, all the people in the crowd are gathering before me and I am feeling slightly as I stand beside my stage and it is difficult to say how many people are here today, but we are aiming for 250, it looks pretty full to me and I am hopeful that at the count we will have got the number we need! I am slightly nervous, but I am sure that I will be fine once I get up onto my stage...

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But this is a truly unique occasion... and a wonderful opportunity for people to learn and spread some awareness and stop Deafblind people from becoming isolated...
 ”

Event official:

Ready, 3, 2, 1, Blows whistle... Applause...

Emma (over the tannoy / speakers):

Right, working in pairs, decide which one of you will be the writer and which will be the receiver... What I want you to do it to spell something to your partner, it can be whatever you want, and see if your partner can guess the word... OK...

Richard K:

So, I am Richard Kramer and I am the CEO of Sense, it is fantastic to see everyone have a go, communicate and everyone has said they will have a go, and they're going to go home and teach their names to their loved ones and their children so hopefully we can spread the word that people communicate in so many different ways...

Emma (Back to the lesson):

X, Y, Z... (applause and screaming)

Emma:

Crikey I was nervous teaching the lesson to begin with, but it became something of a thrill; it was brilliant and felt just wonderful! Achieving an audience of over 350 people was just brilliant and I have every hope that next year we can double it or even more! That would be absolutely fantastic!!!

Peter:

The record attempt there organised by Sense and the accountancy firm Mazars, And you heard Emma Boswell there speaking through her male interpreter.

18m 27Sec

Written by Emma Boswell, National Usher Co-ordinator, Usher service, Sense UK and Chair of DbI Usher Network.

DbI Youth Network Activity Zurich 2018

Simon Allison reports:

The DbI Youth Network (DbIYN) held an event in Zurich, Switzerland during early June 2018. A series of activities were kindly funded through Tanne, the Swiss centre of competence for the Deafblind. Each day provided many opportunities for the young people to experience Swiss culture with their network friends.

As with previous youth network activities the event commenced with a guided city tour followed by sharing a meal together. Our tour guide Anne Maria paid careful attention to the entire group, so each part of the tour agenda was accessible and tactile. The venue for the meal was the Zurich Zeughauskeller that served a range of traditional Swiss food.

Our first full day started with a visit to the Zurich Thermalbad. These are a series of Roman style Spa baths that source pure spring water containing many valuable minerals. The rooftop pool overlooking the city bubbles away at 41 degrees centigrade! Feeling very relaxed the afternoon was spent on Zurich's very own mountain, Uetliberg. The cable car ride to the mountain top was quite thrilling high above Lake Zurich. Switzerland is famous for many things one of which is Fondue. With pans full of hot cheese and pieces of bread we all sampled delicious fondue at the mountain restaurant. Again, a very sensory experience!

The following day it was an early start as we took a boat trip along Lake Zurich. In beautiful sunny weather our destination was Kilchberg and the home of Lindt chocolate. We were all privileged to participate in a Lindt chocolate experience activity where our 'chocolatier' informed us about the process of making chocolate and some secrets about why Lindt chocolate tastes so good! Of course, no chocolate experience is complete without a tasting session and everyone participated in eating many many samples of different types of chocolate. Before heading back on Lake Zurich, we spent the afternoon swimming in the Lake as the temperature was very pleasant. During the evening we visited a bowling alley where everyone enjoyed some friendly competition as we bowled several full strikes and ate dinner.

The final day of activities took us to the Swiss National Museum. The museum had prepared a special tactile tour, learning about Swiss culture, history and traditions. There was even an exhibition about Swiss food, with even more chocolate to sample! We said our goodbyes in the afternoon following lunch sat outside the museum restaurant. The temperature was so hot we needed the cover of the shade.

The Zurich event was enjoyed by all those who attended including young people, support staff and interpreters. The fact that we all used different languages and different methods of communication added to the enjoyment as the sense of achievement in making conversation made us all feel proud.

Santeri Grönlund a youth network member from Finland commented on his Zurich experience, "I enjoyed all the activities as they were all suitable for someone who is deafblind"

Jenny Gillies from the UK was attending her first youth network event and really enjoyed the visit to the Lindt



Thomas, Santeri, Ness, Jenny and Ella on Mount Uetliberg



Group Photo on Zurich mountain



Santeri and Veera enjoy the Lindt Chocolate experience



Enjoying fondue on the mountain

factory, "The chef was great as he told us all about the process to make chocolate and all the different varieties. I tasted so much chocolate I couldn't get to sleep that night. I made some new friends on the trip. I liked talking with Vanessa from Australia as there are lots of similarities between Auslan and British sign language. Learning some Finnish sign language was interesting; it meant I could talk with Santeri. I also made friends with Tesfaldet from Switzerland who told me all about his life and how he has managed to get a job".

Vanessa Vlajkovic from Perth Western Australia also commented on her time in Zurich, "I met so many new and awesome people in Zurich. My favourite activity was the thermal spa, it was extremely relaxing and a

brilliant way to just chill out while making friends. The young people that I met this time will forever be my friends and hopefully I will see them all again in the future for more events that DBIYN organises. All around a terrific trip".

A very special thank you to Mirko Baur from Tanne for making the event happen and to Maya Streich also from Tanne who acted as our guide, whenever we became lost! The network is now planning its activities for 2019 hoping these will be as memorable as our time in Zurich.

Simon Allison-Youth Network Coordinator
(simon.allison@sense.org.uk)



23-27 November 2019
Saint-Petersburg
Russia

This year the conference will be held at the amazing and cultural capital of Russia – Saint Petersburg. The conference is a big event for talented students, graduate students and young scientists from Europe, Asia, America and Russia who are interested in research issues related to dual sensory impairment/deafblindness.

www.deafblindacademy.ru/conf2019

Australia

Deafblind Information Hub

by Senses Australia



Senses Australia has recently been successful in obtaining an Australian Government grant for \$475,000 to establish and implement a National Deafblind Information Hub. This project will be implemented over the next two years and is an interactive on-line resource. The hub will build upon the existing Deafblind Information website previously developed by Senses Australia (www.deafblindinformation.org.au).

The aims of the Deafblind Information Hub are:

- To provide information specifically tailored to Australian's who are deafblind and their support networks about the National Disability Insurance Scheme (NDIS), the new funding model for people with a disability in Australia;
- To provide information to service providers and community organisations on how to effectively interact with a person who is deafblind;
- To provide information on provide accessible information and environments to Australians who are deafblind;
- To provide a Deafblind Consultancy service to individuals who are deafblind and their family members to support them in navigating the NDIS;
- To develop a National Peer Mentoring Program for Australians who are deafblind.

State Government funding to provide information to people with deafblindness

Senses Australia were also successful in gaining a \$120,000 grant from the Western Australian Government to assist Western Australians with deafblindness, as well as those with a single sensory impairment, to understand the National Disability Insurance Scheme (NDIS) and to engage with it. This new funding model for providing disability services in Australia is proving challenging for many people with disabilities to understand the new concepts and processes. Senses Australia ran six workshops with sign language interpreters and 15 individual sessions to support people with deafblindness or single sensory impairments better understand the scheme.

Ending the Isolation Project

Ongoing research to develop a valid and reliable screening tool to identify older Australians with combined vision and hearing loss is underway by Senses Australia in collaboration with Curtin University and the Australian Government Department of Health. The tool was developed using a Delphi method and is currently undergoing validation assessment. In this phase, the screening tool results of 350 participants will be compared to their pure tone audiometric,



field of vision and visual acuity results. In addition, a number of resources have been developed as part of this project including an information booklet and a training video for staff in aged care settings.



Senses Australia, with \$195,888 of grant funding is developing an app to support people with vision impairments to access support via their mobile device to orient themselves in the community and travel independently. Market research was conducted prior to the development phase and it identified that those who might use this technology require a fail-safe system, whereby

if they activate it, they will always receive a response. As a result, a pool of volunteers is being recruited to ensure all calls are answered. A local app development company has been engaged and this phase is nearing completion. When used, the app activates the camera, microphone, GPS and compass of the user's smart phone to assist their helper effectively direct them to their destination. The app is now undergoing trialling before being launched.

Canada

Deafblind Ontario Services Position Paper: Recognize Deafblindness as a single disability: Open Your Eyes and Ears

In early 2017, DeafBlind Ontario Services created a position paper, "Recognize Deafblindness as a single disability: Open Your Eyes and Ears," to highlight the rights of Canadians who are deafblind within the context of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

The convention ratified by Canada in 2010, is an International human rights instrument to promote respect for their inherent dignity, as well as protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms for all persons with disabilities.

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

The position paper further calls for the following key recommendations:

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

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

The organization additionally presented the position paper on a panel, *Discrimination Against Marginalized Groups and Differential Access to Institutions* at the Realizing Rights 2017 conference, June 8–10th in Ottawa. This annual conference organized by the Canadian Association of Statutory Human Rights Agencies (CASHRA) featured presentations and panel discussions from provincial human rights commissions, staff, lawyers, and advocates from around the world.

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

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

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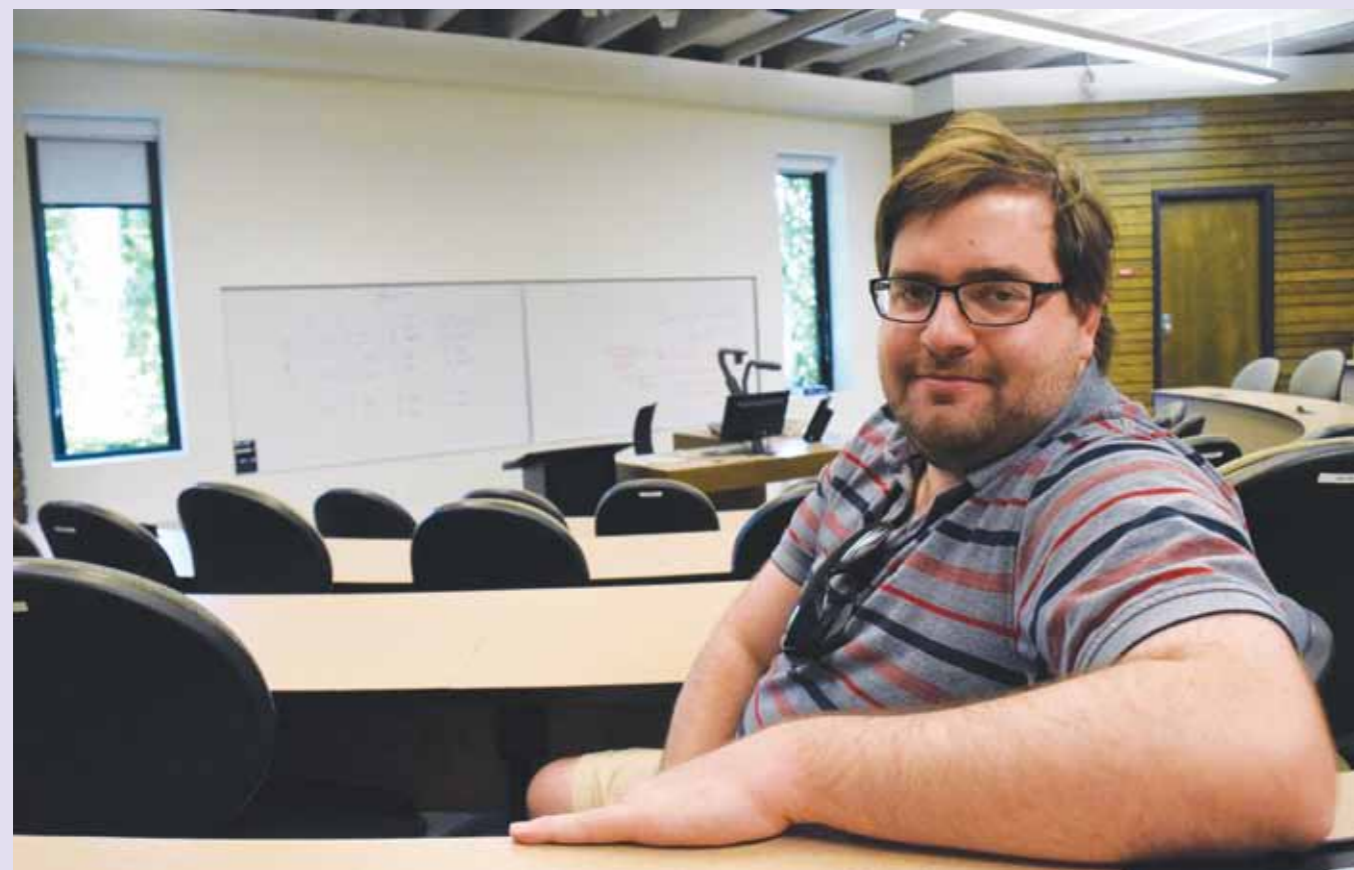
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Canada continued

Breaking Down Barriers with the Help of Intervention Services

by Brian Shypula

Michael McNeely is taking his passion for accessibility and breaking down barriers for people with disabilities to a new height in Canada.



Michael, who is deafblind, will be armed with a law degree specializing in human rights and advocacy when he graduates from Osgoode Hall Law School at York University in 2020.

“Obviously there are still a lot of things challenging deafblind people that don’t need to be, there are a lot of challenges that exist that could be taken down,” Michael said, listing barriers to public transportation and not enough hours of Intervention Services as two things

he wants to have changed. In an interview, Michael talked about his experiences at law school, his goals and the difference Intervenor Services have made in his life.

Michael, who is deaf and partially blind, began to receive Intervenor Services through Canadian Deafblind Association Ontario Chapter in 2006¹. It was a turning point in his life. He was able to fulfil a dream and attend Queen’s University in his hometown of Kingston, Ont. “In some ways I still

know that my life would be much harder if I didn’t have Intervenor Services support and I wouldn’t be doing half of the things perhaps that I’m able to do now,” Michael said, such as attending law school.

It’s important to Michael to give back. He runs a disability advocacy club at Osgoode and has a placement with the ARCH Disability Law Centre in Toronto, a specialty community legal aid clinic dedicated to defending and advancing equality rights of

people with disabilities in Ontario. Ultimately, Michael wants to work on behalf of people with disabilities, refugees and the LGBT community in both human rights and criminal law as a practising lawyer. “Ideally I’d like to work with clients that I find meaningful and I relate to what their experiences are,” he said. As far as he knows, he would be the first deafblind lawyer in Canada.

Haben Girma, the first person who is deafblind to graduate from Harvard Law School, congratulated Michael for entering law school. She said she knows of only three other lawyers in the United States who are deafblind and one in Finland. “I hope it gives people a smile to know someone is doing law school for the disability community,” Michael said.

Michael is no stranger to higher education. He earned a master’s degree in education from Queen’s in 2013 and undergraduate degrees in education (2011) and English and literature (2010). Michael said he is pleased with accessibility-related services he is receiving at York. The university is not supplying real-time captioning of lectures but agreed to provide professional notetaking services and pick up the costs of intervenors who attend classes to support Michael. CDBA Ontario negotiated support for three part-time intervenors with York.

The professors in Michael’s classes are connected to his FM system, which transmits to his cochlear implant enabling him to hear what

they say during lectures. However, the FM system does not pick up questions, comments and answers by his fellow students. Michael said he must ask the professor or his intervenor to repeat what other students say in class. Intervenor Carolyn said there was one instance when the Wi-Fi malfunctioned in class. She helped troubleshoot and managed to connect an iPad so that she could write notes for Michael that class.

Otherwise, notes from the professional note takers come to Michael in near real-time via a Google doc. “It lets me stay focused on digesting the information and not have to worry about keeping up,” he said.

Michael took seven courses in Year 1, one more than most of the students in the program. He applied and was accepted into a “bonus” class on legal theory offered to only 20 first-year law students. Michael said he was drawn to the class because of its small size, something he prefers and is accustomed to from graduate school.

“Ultimately, Michael wants to work on behalf of people with disabilities, refugees and the LGBT community in both human rights and criminal law as a practising lawyer.”

If he weren’t busy enough with second year law, he is also taking a course at George Brown College to complete a certificate in editing. He is on an editing placement at George Brown College working on a number of LGBT magazines. And the film buff reviews films part-time for the online site That Shelf, including some entries in the 2018 Toronto International Film Festival (TIFF) and beyond. He was proud to receive media accreditation for TIFF 2018.

Michael was accepted for the law programs at both York and the University of Windsor. He chose Osgoode at York because of its reputation in human rights and advocacy. It also enabled him to stay in Toronto instead of moving to a new city where he would have to start over in many respects. But he may never get used to the slower pace of suburbia where the York campus is located in the north end of Toronto. “I guess life here is kind of boring, but that means I should be doing my homework if I feel bored,” Michael quipped.

“Michael took seven courses in Year 1, one more than most of the students in the program.”

¹ Canadian Deafblind Association Ontario Chapter (www.cdbaontario.com) is a large corporate member of DbI.

India

Celebrating Two Decades of Inclusive Practices

National Conference Jointly Organised by Sense India & ICEVI

The Sense International India and West Asia Region of the International Council for Education of People with Visual Impairment (ICEVI), both, leading organizations in the field of deafblindness and visual impairment held a joint National Conference at Ahmedabad Management Association hosted by the Blind People's Association and Sense India from 8–10 December, 2017.

The Conference was inaugurated by Shri Kamlesh Kumar Pande, the Chief Commissioner of Persons with Disability, Government of India.

The objectives of the Conference was to equip educators, professionals, parents and people with visual impairment and deafblindness about advancements in the field related to technology, communication, learning strategies and related matters.

The Conference brought together around 410 delegates from the West Asian Region. The leaders from international organizations like the ICEVI; Perkins International, USA; Sight Savers International; CBM; Vision 2020 India and others from countries like USA, South Africa, UK, Australia and countries of West Asia participated.

Lord Low of Dalston (Colin Low), Former President of ICEVI set the tone for the Conference by his Keynote Address in the inaugural function. All the officials of ICEVI and of Sense

International India remained present throughout the Conference. There were 6 plenary sessions and 16 concurrent sessions and 64 paper presentations. These Papers were presented on the topics of Inclusive Education, Inclusive Employment and Advocacy for Inclusion.

Sense International India conferred "Jagdish Patel Award on Shri Arun Doshi, posthumously for his outstanding contribution for improving the quality of education and rehabilitative services for persons who are deafblind in rural Gujarat. The Late Jagdish Patel was a visionary who started numerous Institutions in Gujarat helped the entire state to develop resources. Mr. Patel was blind and in later age became deaf. In spite of his multiple disability, his dynamism and intelligence remained undiminished. In his memory, the "Sense India: Jagdish K. Patel Award" has been set up. This Award function was held along with an entertainment programme.

Mr. Kamal Dayani, Principal Secretary, Department of Social Justice & Empowerment graced the Valedictory Function as Chief Guest. Mr. Richard Hawkes, CEO, British Asian Trust (Former C.E.O. Sense International UK) who was instrumental in setting up Sense India, spoke about the origin of Sense India and the achievements over 20 years. Richard also launched 'Handbook on Curriculum Adaptation for Inclusive Education of Students with Deafblindness', developed and published by Sense India.

Sense India was founded 20 years ago for promoting services for deafblind people. Sense India brings together and supports professionals (such as educators, administrators, researchers, medical specialist etc), families and deafblind people to raise awareness about deafblindness. This joint conference celebrated 20 years of Sense India and also 20 years of implementation of the Persons with Disabilities Act.



Jordan

An ideal educational environment for learners who are Deafblind

By Brother Andrew Decarpentier¹

I wish to share some of my experiences of children with Deafblindness in a Unit for the Deafblind; part of a School for Deaf and Deafblind Children in the Middle East.

In fact, what was originally referred to as a 'Deaf School' we now call a 'Sign Language School', following the good example of our colleagues who run such schools referred to as: English Middle Schools; or American, French, Korean, Turkish- Schools according to whatever language medium is practised. A Sign Language School is not necessarily a School for the Deaf, although most of its students will be Deaf. It is effectually a school which caters to everyone who wishes to enjoy an education through the medium of Sign Language. This could include hearing children of Deaf parents and it would certainly include children who are deafblind.

It must be obvious to all that the best learning environment for deafblind children will be a 'sign language school' that is populated by a majority of Deaf signers. The exceptional aptitude of Deaf children for signed languages, both in the sense of learning, expression and reception (including their interpretation of variations that are derived from general sign language – such as a local tactile sign language), makes for much greater ease, as well as broader and better communication. Indeed, the environment itself would take us half-way already towards solutions for their peculiar problems. Experience bears this out.

A 'School for the Deaf', i.e. a 'Sign Language School', provides

for a community of 'signers' who easily and rapidly develop the communication skills that children with deafblindness require. The school community of staff and students, who together would number scores or even hundreds of sign language users, provide the perfect language environment for learners with deafblindness. Where else would there be such a large community of 'signers' that share a familiar cultural environment and an expert language community for these children to develop and flourish in? It is certainly better than a school for children with blindness who have no use for sign language; and better yet than a select community of children with deafblindness, who have problems discerning the presence of other deafblind persons around them to begin with.

Another great advantage of the implementation of such a policy is that the 'Special School for the Deaf' changes into an 'Inclusive Sign Language Medium School'. Sign language-based education becomes perfectly normal (while the quality tends to improve), but those who are deafblind or others with co-occurring disabilities who have either regular or tactile sign language skills, would form the 'inclusive element'. The traditional 'special school' (in the sense of segregated) has become an Inclusive Sign Language Medium School that is ready to receive

one and all who would be happy and feel enabled in such an environment.

In addition, learners with deafblindness who are mainstreamed in a sign language school, whether they follow the regular curriculum or a special adapted programme, will help educate the deaf community as well as the community at large about their needs, skills and abilities as well as their surprising and wonderful potential.

In developing countries, too often children with deafblindness lag behind. One very useful and simple way forward could well be to support at least one so-called 'School for the Deaf per country or region, i.e. create an 'Inclusive Sign Language School' that will welcome the deafblind community. Try it. You will see that it works!



Brother Andrew Decarpentier

Brother Andrew Decarpentier
(decarpentier.andrew@gmail.com)
SALT, Jordan, October 2018

¹ Brother Andrew, now retired, formerly worked at The Deafblind Unit at the Holy Land Institute for Deaf and Deafblind Children, in Salt, Jordan.

Russia

The Network of Resource Centres for the Deafblind in Russia: Joint Experience with Perkins International

by Dmitri Polikanov

There is a growing number of children in Russia identified with combined vision and hearing impairments including those with multiple impairments. There is also an obvious lack of teachers for these individuals.

To resolve this problem, we have decided that we need to create a regional network of professionals and establish a list of services available in the regions of Russia. This network could be a good point for testing and disseminating the new teaching methods, some of which are being developed in our touch-base center “Yaseneva Polyana” in Moscow. Besides, such project would help to establish in Russia accepted international practices and arrange for academic exchanges. Through such education of practitioners, we plan to encourage some of them to continue research career, to write academic papers and, hence, contribute to maintaining the Russian scientific tradition and school of science.

The centres that we open in the Russian regions are aimed at training specialists to work with children with combined hearing and visual impairments and multiple disabilities; at counseling and supporting families who are raising children with combined hearing and visual impairment and multiple disabilities, as well as developing individualized educational programs for them.

What is our plan? We have a three-year program to train the trainers in 40 regions with the highest deafblind population. They will pass a three-level training course with Perkins International, which we have adapted to the Russian audience and translated. We will make that they are internationally certified and get a certificate from the Russian Ministry of Education as well after passing through the specifically-designed evaluation system. Beside the offline activities, we will produce a Russian-language version of the online course, which will increase the availability of this service to a larger number of teachers across the country.

It is important that key and promising trainers get access to extra options, such as internships, summer schools, fellowships and are involved in the system of permanent sophistication of skills.

The Ministry of Education helps with the certificates and provides for some burden-sharing. In Russia the educational services are mainly the prerogative of the regions, so we had to sign over 40 agreements with regional authorities, which will be responsible for equipping the

centres and providing the salaries for the specialists.

So far we have seven resource centers operational. A group of 28 highly-motivated students from 22 regions attended the first training module (off-line, 11 days, including Saturday) in January – February 2018. They all now practice the new skills in their regions, report to us on their activities and should take Level-2 course in late 2018-early 2019. The online version of the first module is now available in Russian as well. Moreover, one person attended the Summer Institute in Perkins in 2017 and another students spent 9 months at the ELP program there.

What are the lessons learnt by now? First of all, it occurred that the students mostly know the basics of work with the deafblind children, so they mostly need refreshment of the foundations. At the same time, it is important that they study new approaches (because in some cases the Russian and U.S. approaches to communication or the development of the effective curriculum differ) and see how to make focus on the child.

Secondly, there were language issues of course. This related to the terminology, but also to the



Dmitri Polikanov

fact that there is not much international literature translated into Russian in this sphere. So we are thinking about creating an extra reading list for that purpose.

Thirdly, it is important to enlarge the geographical scope of approaches, so we plan to have the students acquainted with European concepts of working with the deafblind, etc.

Our next steps include the design and adaptation of the Level-2 course and the proper evaluation system. We want to use students as volunteers in our project of summer schools for the parents. Such schools bring together parents, their children, teachers of the kids and high-level experts, who share their knowledge and skills. In this co-working space our students will have a chance to get new first-hand professional experience.

Besides, each student will have some homework to do in between Level-1 and Level-2 courses. They do video recording of their work with the children and have to perform certain assignments. We also hope that these assignments will provide the food for research for some of them.

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Such schools bring together parents, their children, teachers of the kids and high-level experts, who share their knowledge and skills.

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REGIONS TARGETED BY THE PROJECT

Altaisky krai • Astrakhan Region • Republic of Bashkortostan • Belgorod Region • Volgograd Regionk • Volog Region • Voronezh Region Kaluga Region • Kaliningrad Region • Irkutsk Region • Tyumen Region • Tula Region • Tver Region • Tambov Region • Stavropol Territory Sverdlovsk Region • Saratov Region • Republic of Sakha (Yakutia) • Republic of Daghestan Republic of Adygeya • Novosibirsk Region Novgorod Region • Nizhny Novgorod Region Moscow • Leningrad Region • Krasnoyarsky krai Krasnodarsky krai • Ulyanovsk Region Republic of Khakassia • Chelyabinsk Region Yamal-Nenets Autonomous Area • Yaroslavl Region • Republic of Karelia • Republic of Tatarstan • Udmurtian Republic • Rostov Region Samara Region • Omsk Region • Permsky krai

“ We have a three-year program to train the trainers in 40 regions with the highest deafblind population. ”

Russia continued

Art therapy group training “Communication via creativity” with children having multiple disabilities¹

by Alina Khokhlova and Daria Salnikova

Children of early age with severe visual and hearing impairment including intellectual disabilities have significant difficulties in the development of the communication.

They may demonstrate no reactions to an adult for a long time; not distinguishing relatives from strangers; being passive in response to emotional expressions of people up close. Further development of the child’s communication largely depends on proper interaction with adults close-by, with the child choosing appropriate communication tools available to them.

Clearly, the need is well recognized for purposeful development of effective communication skills, ensuring that conditions for productive interaction with others is an important factor for successful intervention during preschool and primary school age periods.

The *American Art Therapy Association*² defines art therapy as: “an integrative mental health

and human services profession that enriches the lives of individuals, families, and communities through active art-making, creative process, applied psychological theory, and human experience within a psychotherapeutic relationship”.

The concept of art therapy also includes music therapy, dance and movement therapy, drama therapy and some other methods for children, adolescents and adults.

Art therapy can be successfully practiced with clients having physical, mental or emotional problems, diseases and disorders. The experience of using art therapy in working with children with autism, mental retardation and movement disorders was described in psychological and pedagogical articles (Charman & Baron-Cohen, 1993; Krasniy, 2014). Many organizations in the world

that support deafblind people have such experience, too. These include theatre performances, dance, sculpture, painting.

Art therapy is based on the belief that art-making within a therapeutic context supports changes in a person’s inner world and helps them develop a more integrated sense of self.

This article presents a program of communication training for children’s with dual sensory impairment through the process of joint creativity, which is based on the model of group art therapy.

The program of training: “communication through creativity” was created on the basis of the “Summer School” for children with hearing and visual impairments and their families, organized by the Moscow Resource Center “Yaseneva Polyana” and Deafblind Support



Foundation “Con-nection”. Summer schools take place once a year and involve up to 12 families with children having deafblindness and their siblings. We are convinced that this is a group where forms of creative communication are developed and improved; allowing to support or to compensate individual expressions of participants. That makes it possible to solve the following tasks.

- Improve the quality of communication between the child and adults;
- Develop the empathy of a child with complex disabilities;
- Teach the child to come into contact with peers;
- Increase the level of random regulation of general activities.

IN THE COURSE OF THIS TRAINING, WE FOLLOW SOME RULES:

- 1. Ensure the child is comfortable.** If the child doesn’t participate in the game, we do not force it. The reason for this may be their poor state of health, a lack of mood or interest in this activity at the moment. We can wait until the next time, when he/she has a desire to communicate. The child can get used to group activities gradually. Even if he/she does not enter into open contact with other participants or communicates only with the accompanying adult, he feels the presence around other people, adults and children doing the same as he or she.
- 2. Emotional involvement with adults.** Communication with the child should be emotional and accompanied by facial expressions and gestures.
- 3. Organize the space the choice of materials.** The space should be arranged so that the child could use all their senses to the maximum, using all available channels of interaction with the environment.
- 4. Variety of means and results.** Children together with accompanying adults produce a creative product as they see fit, using all available means, at their own pace.
- 5. Having a finished product available from the activity.**
- 6. Focus on involvement to ensure pleasure in the process, not just the quality of the product.**
- 7. Ensure ease and simplicity of the task using simple instructions.** Topics of the training sessions should be selected taking into account age differences and individual characteristics of all participants.

¹ Paper was presented at the Young Researchers Conference in Moscow, October 2018

² <https://arttherapy.org>

Russia continued

All art therapy classes consist of two parts: music therapy and art.

For the musical part we choose Russian folk songs for children because of their simple melody and rhythm, with words repeated many times.

The program for children with deafblindness and their families includes from 8 to 10 meetings.

For most of the sessions we need a large table around which all children and assistants can sit for meetings. Some of the joint sessions might be created by sitting on the floor or other comfortable places in the room. Also, a sufficient number of art materials must be prepared in advance.

The end time of the meeting can be different because some children cannot concentrate on one activity for a long time or they become quickly tired. Every participant can finish working at his/her own time.

To sum up, we think these art therapy sessions help children to be included in joint activities with adults and peers, help develop an emotional response to cooperation with the desire to communicate.

Alina Khokhlova (PhD in psychology) is a psychologist at the Resource center supporting persons with deafblindness and their families “Yaseneva Polyana”, and assistant professor at Moscow State University of Psychology and Education.

Daria Salnikova is a Master’s student at Moscow State University of Psychology & Education and volunteers at Deafblind Support Foundation “Con-nection”.

AN EXAMPLE OF THE PROGRAM

1st day	The participants pass the ball in a circle, calling out their names. Parents or the assistants can name the children if necessary. To make hand prints on the paper: the hands of a child are painted with finger paint, then he makes an imprint on the paper. The result is a common panel with colored hands.
2nd day	Singing, dancing and playing instruments; Making beads of clay with holes in them.
3rd day	Singing, dancing and playing instruments; Coloring T-shirts with acrylic paints and markers.
4th day	Singing, dancing and playing instruments; Painting beads with acrylic paints.
5th day	Singing, dancing and playing instruments; Stringing little beads on a thread.
6th day	Singing, dancing and playing instruments; Making models of themselves from plastic.
7th day	Singing, dancing and playing instruments; Putting figures of themselves on the paper and drawing background with theme: “We are on the sea”.
8th day	“Tree of Happiness” theme: participants cut out and decorate ornaments, which are then glued on the panels with a large tree painted on top of the paper.

For more information about this program, contact **Alina Khokhlova** (ehalina2@yahoo.com) or **Daria Salnikova** (darya.salnikova@mail.ru)



Daria Salnikova and Alina Khokhlova

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Sweden

Ready-Ride Helps Persons with Blindness and Deafblindness to Ride More Independently

by Parivash Ranjbar

Horseback riding is the largest sport for disabled people in Sweden and is often used for rehabilitation purposes. Riding is accepted by the state as well-being and its costs can be paid by the employer. Persons with deafblindness, blindness, cerebral palsy, attention deficit hyperactivity disorder, etc can obtain a prescription from their doctor, which shows the importance of riding as therapy in Sweden.

Riding is difficult for people with deafblindness because they do not see their position in the arena nor can they communicate with the instructor using sound. The only possible way is stop the riding is to use tactile communication for information transfer and feedback.

Figure 1A shows the rider with deafblindness and her assistant walking close to the horse prepared to inform the rider instructions given by the instructor. Figure 1B shows that the instructor has stopped the rider to give her feedback/new commands via the tactile sign language interpreter. The communication via sign language takes time and the riding becomes not effective.

The vibrotactile aid ‘Ready-Ride’ solves this distance communication problem. It was developed by a research team at Örebro University and the Audiological Research Centre at Örebro in Sweden with the aim to make it possible for persons with deafblindness to communicate from a distance.

In Sweden, Denmark and Finland this tactile aid is used of persons with deafblindness when riding, rowing, biking, walking or shopping in large malls with small passages. The instructor, leader or family member holds the sender in her/his hand while the user with deafblindness puts the receiver in her/his pocket or waist bag with vibrators placed on different positions of the body or helmet when riding or biking. The user with deafblindness and the instructor agree on



Figure 2: Ready-Ride

vibrator positions and what each vibrator will announce. Usually they place the vibrators on the right or left side of the cheek with the clip on the



Figure 1A: The assistant walking beside the horse to guide the rider



Figure 1B: The instructor informing the rider via interpreter

Sweden continued



Figure 3: The Rider and her instructor using the Ready-Ride

helmet to signal “Turn right”, or “Turn left”; a vibrator under the jaw will notify “Start”. The fourth vibrator can be placed anywhere on the body to signal “Stop”. The information can also be coded as Morse code, or combined short and long pulses.

Ready-Ride has been tested by persons with deafblindness and blindness when riding (See Figure 3), rowing (See Figure 4 and the clip www.youtube.com/watch?v=N0Mq5GsPNVc&t=95s), biking or walking. In general they could easily use Ready-ride without requiring long introduction and guidance to get started. According to the users the vibrations are intuitive, easy to detect and distinguish. Ready-Ride is mobile device that can work anywhere without any need to adapt to the environment. The system gives the rider tactual information without disturbing other persons or horses nearby. Using Ready-Ride the riders got more time to ride since they could communicate while they continued riding. The quality of the riding lesson increased as they could get immediate feedback directly. A mother who has tunnel vision and uses an electric wheel chair needs guidance when taking walks with her child and when she is shopping in a big shop with small passages where there is not enough space for her and her assistant walking beside each other. Using Ready-Ride, her assistant can guide her from

distance allowing her to freely go around in the shop or take walks with her child, keeping their privacy.

Ready-Ride has been evaluated and the results are published. It is available at the company Pariception AB. One can read more about Ready-Ride and other vibratory aids as Ready-Move, Monitor, Distime, Good vibrations and VibroBraille on www.pariception.se



Parivash Ranjbar

For more information, contact
Parivash Ranjbar by email:
parivash.ranjbar@pariception.se

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According to the users the vibrations are intuitive, easy to detect and distinguish.

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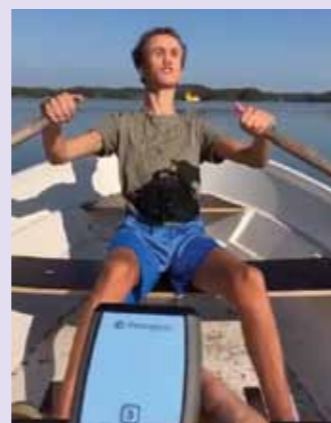


Figure 4: Person with deafblindness rowing with guide using Ready-Ride

Switzerland

An international congress in the Swiss Alps finds new creative ways

Conferences and meetings are many things, but often they not very effective, according to Mirko Baur, General Manager of Tanne¹, the Swiss Foundation for the Deafblind.

Conferences offer a variety of short presentations and workshops; while exciting and stimulating, the results are usually not sustainable. Much of the itinerary involves too little activity; and while cognitively appealing, offer little in terms of sensuality and emotion. The time available is usually too short for collegial exchange or to draw conclusions for one’s own practice. In addition this offers little in the program for our clients, who are actually the focus of the program, but who often only play a supporting role in these conferences.

With these thoughts in mind, Tanne, together with Oberlin Lebenswelten of Potsdam² sought a new congress approach to turn this situation around and create something else – a creative international congress to benefit the individuals we are dealing with every day. The result was the successful conference ‘Self-Expression and Congenital Deafblindness’ held 14 to 16 June 2018, at the Swiss Health Resort in Bergün, Switzerland located in the middle of the UNESCO world heritage mountain landscape between the Swiss Thusis and the Italian Tirano.

Three theatre groups, starring people with deafblindness from Italy, Germany and Switzerland, were featured as centre pieces of the program. Workshops with topics that served to touch one emotionally, were further program highlights. There were two

stimulating key note addresses that were intentionally kept short. The boutique size of the conference totaling 80 participants, of which a number were artists, allowed for a lively exchange. A film project also appealed for everyone.

According to feedback from participants from Australia, Germany, the Netherlands, Italy, Norway and Switzerland, this event was a success and will be remembered as having a lasting effect.

Some comments include:

- The mixture of content contributed to its success.
- The long breaks were welcomed and allowed for exchange and reflection.

- The presence of people with congenital deafblindness was special to the conference; their being not only central in the theatre performances but through their participation in workshops, the film project and the gala night.
- Popular workshops included: Different practical aspects of self-expression featuring people with deafblindness; Katherine Biesecke’s workshop on ‘Rejection, shame and disgust in daily work’ and René Berera’s workshop: ‘Sounds of life: self-expression through musical means’.

Good intellectual content was spread throughout the event in keynotes and workshops.



Workshop Land art: From individual experience to creative self-expression

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

² <https://oberlin-lebenswelten.de/startseite>

Switzerland continued

Mirko Baur's keynote address at the opening of the congress introduced a definition of self-expression based on current philosophical and neuroscientific discussions. With photographs of sculptures by the Norwegian artist Gustav Vigeland, Anne Varran Nafstad's keynote address

showed how we read attention, intentionality, and meaning into the physical expression of the Other. It became clear that our intuitive readings reach their limits in the context of congenital deaf blindness: Because affected people can confront us with other forms of self-expression.

All the more connecting was the joint film project! Organized in groups, it was about tracing those moments in which each is in their own element. In the here and now of the congress days or logically-reflexively with a look back at one's own educational biography: what did education and upbringing contribute to this? And what does this mean for a pedagogy that wants to promote and strengthen self-expression in people with deafblindness? The groups presented their results in short film sequences. A professional film crew developed an approximately 15-minute congress film from this, including supplementary interviews and theatre shots. The film can be viewed at: www.tanne.ch/aktuell. The film shows the highly expressive nature and architecture of the conference venue, bringing the congress atmosphere to life.

This conference demonstrates a different and creative example of what future national or international congresses could look like.

Mirko Baur (general manager of Tanne) and Katherine Biesecke (Oberlinhaus) were the organizers and co-hosts of the conference. For more information about the event, contact (mirko.baur@tanne.ch)



Congress-Film



Congress Venue Kurhaus Bergün (Source: Kurhaus Bergün)



Photo: Plenum Room Congress (Source: Kurhaus Bergün)

“ This conference demonstrates a different and creative example of what future national or international congresses could look like. ”

Introduction to Assessment Series

This is the first in a series of articles about the assessment of children and youth who are deafblind, with an emphasis on those who are prelinguistic to early linguistic. This paper will ground the series by sharing basic principles and guidelines for assessment. Later papers will address specific assessment instruments and sections of those instruments that might be particularly helpful when assessing learners who are deafblind.

ASSESSMENT ARTICLE #1

Assessment of Learners who are Deafblind: Basic Principles and Guidelines

By Susan Bruce, Boston College, and Chris Brum, San Diego State University

Assessments are conducted for different purposes, including screening for a potential disability, diagnosing a disability, learning more about a student's performance in a selected learning domain (such as communication), creating an individualized curriculum or program, evaluating student learning/progress in relationship to the curriculum being offered, and evaluating program quality (Brown Snell, & Lehr, 2011; Bruce & Ivy, 2017). It is important to select assessment instruments and procedures to match the purpose of the assessment. This series of articles will focus primarily on the types of assessments that occur in school settings, for the purpose of knowing a student's current level of knowledge/skills in specific learning domains. This information is then used to develop individualized instructional goals and programming.

Types of Assessments

Formal assessment instruments include highly structured procedures for administration of the instrument and for scoring. They may be norm referenced (comparing an individual's performance to the performance of others) or criterion referenced (comparing an individual's performance to an established criterion or achievement level). When norming groups are provided, it is important to know if children and youth who are deafblind were included and to disclose this in the assessment report. Formal assessment instruments usually include recommended qualifications for the assessor which may include educational level and knowledge of statistics. Often formal instruments include a manual or set of directions that tells the assessor exactly how data must be collected (such as through direct testing, observation,

or report of others). They also provide guidelines about the age span for whom the instrument is appropriate. Commercially produced assessment instruments may be formal or informal. Examples of formal assessments that are appropriate for use with some children who are deafblind include: Developmental Assessment for Individuals with Severe Disabilities (DASH-3; Dykes & Mruzek, 2012); Callier-Azusa Scale (Stillman & Battle, 1985); and INSITE Developmental Checklist (Morgan & Watkins, 1989).

Informal assessment instruments are less structured, allowing the assessor to use more procedural discretion. Informal assessment instruments and procedures are more subjective, often more considerate of context, and may be more directly related to instruction (such as in teacher made curriculum-based assessment instruments). Informal assessments include dynamic assessment approaches that change in the moment in response to the child's interests and actions. Van Dijk's approach to assessment (Nelson, et al, 2009; Nelson et al, 2002) and person-centered assessment approaches are examples of informal assessments that are appropriate for learners who are deafblind.

Learner Characteristics to Consider

Before the actual assessment can begin, the assessor must gather information about the learner's characteristics as part of the preparation process. This information includes: etiology of deafblindness (as in CHARGE syndrome), age of onset of deafblindness, types and levels of hearing loss and visual impairment, gross and fine motor skills (and associated positioning requirements), and the impact of the learner's disability characteristics on assessment performance. Additionally, the learner's expressive

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This series of articles will focus primarily on the types of assessments that occur in school settings, for the purpose of knowing a student's current level of knowledge/skills in specific learning domains.

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and receptive modes/forms of communication, level of communication, and the family's language and culture should be considered. If the assessment is being conducted by someone unfamiliar or minimally familiar with the child, it will be important to know how the learner responds to strangers. It may be helpful to include a familiar communication partner in the assessment process who can not only help the child to remain comfortable, but also to support the assessor to better understand and identify the individual's communicative signals. Identifying the learner's preferences through a preference assessment (Logan & Gast, 2001) may also be helpful when selecting toys, objects, and activities to be used during the assessment. Identifying the times of day when the learner is most likely to be alert is critical to planning an assessment that will best capture optimal performance.

It is essential that the assessor be aware of the learner's necessary accommodations across learning domains. This includes physical accommodations, optimal positioning, use of adaptive equipment (prone stander or wedge), appropriate acoustics and enlargement, and assistive technologies. The learner should be provided with the same accommodations as are typically provided for daily activities. When direct testing occurs, this will ensure that the learner is already familiar with the accommodations. Being aware of environmental factors that may affect the individual and their attention is also important, including lighting, auxiliary noises and distracting movements within the assessment space.

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Being aware of environmental factors that may affect the individual and their attention is also important...

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Assessor Characteristics to Consider

An effective assessment process can only occur if the assessor has the necessary knowledge and skills. The assessor must be able to select appropriate assessment approaches and instruments to fit the needs of a specific learner. Whether using a dynamic approach to assessment or a formal assessment instrument, the assessor must be fluent in that approach or instrument. This requires a great deal of preparation by the assessor. This preparation will result in an assessment process that goes smoothly and reduces the need to review assessment items and procedures while in the presence of the learner being assessed. This is especially important for learners whose behavioral/alertness states change rapidly or who may have difficulty waiting.

The assessor should be able to communicate using the learner's preferred expressive and receptive modes/forms of communication. This will support the assessor to establish rapport with the learner and to gather first-hand information. The assessor must provide all appropriate accommodations. Sometimes an assessment instrument is a good fit for a specific learner, but it is necessary to adapt the procedures presented in the manual. If this occurs, the assessor should always disclose those changes in any written or oral report, along with the potential impact on validity. Being able to collaborate with others while conducting an assessment is a critical skill. When consultants (from outside the school) conduct assessments, they are especially reliant on the reports of team members to learn more about the child. Outside consultants need to know if the day they observe is a typical day or not for the child. Assessment findings must be communicated to others, being thoughtful about defining terms and providing explanations. Finally, the findings should be used to shape or improve instruction. While we are required to conduct various types of assessments within specific timeframes, there is an ethical obligation to ensure that the assessment process will provide something of value for the learner.



Susan Bruce

Assessment Instrument and Procedural Considerations

Venn (2014) suggested characteristics of appropriate assessment instruments for use with children with severe disabilities. These ideas are also applicable to many children and youth who are deafblind. Assessment instruments that have many test items will best capture small increments of growth/development. When an assessment instrument has many items, the gaps between items are small, supporting instructional teams to more easily identify potential instructional targets, with consideration paid to what is valued by the individual and family. It is helpful if the administration procedures allow the assessor to collect data from various sources, including interviews, reports of others, observation, and direct testing. It is also helpful if the instrument goes beyond stating the items to also provide examples or clarification. This supports the assessor to identify different ways that the learner can show what he/she knows. This instrument characteristic is especially important for learners who are deafblind because they may need to show us what they know in a different modality (such as showing us knowledge of object permanence through touch rather than through vision). Finally, it is important that the assessment instrument allow for partial and/or prompted level of performance. Often, progress is marked by a reduction in prompts or learning to do more parts of a skill (as in learning to do more within an item on washing dishes). For some teams, it may be important that the assessment instrument provide support for the development of goals, objectives, or the individualized education program. Other procedural concerns include collecting data on more than one day (especially if the learner's performance varies) and in more than one environment. Whenever possible, assessments should be conducted in the context of familiar activities, environments, and materials by people who are already known to the learner who is deafblind. Familiarity will increase predictability for the purposes of reducing the learner's anxiety and promoting engagement.

The next article in this series will give an overview of evidence-based practices in deafblindness, in the area of assessment.

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Diploma in Educational and Social Inclusion – On line

“Reflections on the Training Process. Some Words of tutors and participants”

By María Aparecida Cormedi, PhD and Graciela Ferioli, MA

Introduction

This document is meant to share the process of preparation, programming, execution and evaluation of the continuous training instance through the Diploma in Educational and Social Inclusion that was developed 100% on line by the Faculty of Education of the Catholic University of Córdoba, Argentina.

The diploma had 36 enrollees from different places around the country and from different fields of knowledge: teachers of special modality, primary and middle regular school teachers, supervisors and representatives of families. This diversity of participants enabled and enriched the training proposal, allowing the sharing of different experiences of diversity and inclusion in families, schools and community.

The publication aims to share and reflect on the processes that were experienced by the participants, tutor and coordinator of the course to help the reader to understand a model of theoretical and practical training that was evaluated as successful by participants.

Fundamentals

Educational and social inclusion are rights of every person with disabilities as established by the UN Convention on the Rights of Persons with Disabilities in 2006. However, in the context of social exclusion as it is the current reality in many places in Latin America, educational inclusion in all regular and public schools can be a substantial challenge, which is necessary to overcome.

International legal frameworks establish inclusive education in regular schools for all students with complex communication needs; that is to say, without any exclusion due to their disability, disorders, health vulnerability or any learning difficulties. Consequently, teachers and education professionals need to think about the success of these students in the regular school. The success of learning depends on trained professionals who master knowledge about the specificities of various disabilities, disorders, alternative and augmentative forms of communication, models of individualized

educational plans, and planning support for inclusion, ensuring that students with disabilities and vulnerabilities can access the regular curricular contents according to the principles of universal learning design.

The Diploma is aimed to develop theoretical and practical concepts of educational and social inclusion in order to improve inclusive practices with a focus on the diversity of students. To address these issues, a training structure of six modules was proposed so that participants were able to elaborate and share their best practices and experiences: 1. Organizing inclusive networks, 2. Building accessibility for each student, 3. Valuing communication potential, 4. Facilitating communication, 5 Planning for diversity, 6. Accessing the Regular Curriculum.

Description of the training process

a. Participants' voice

In Module I, reflecting on the Convention on the Rights of Persons with Disabilities, the participants expressed:

“The life of people with disabilities is not reduced to school age only. Although this stage seems to be the most important, once completed, it is essential to think about a professional work future, and also about the possibility of continued learning in conditions of equal opportunities.”

“The change of paradigm implies the implementation of a multiplicity of actions among which are: to align the regulations, train professionals, provide resources to the institutions, sensitize the community and, fundamentally, break with stereotypes and barriers that prevent the group of people with disabilities from being part of the educational community with equality and equity.”

“Besides, when talking about inclusive education, it should be noted that the greatest beneficiaries of inclusion are not children with disabilities, but

their classmates, who will have a broader view and knowledge in the future.”

“In turn, for inclusion to become a reality, it is necessary that policies, cultures and institutional and pedagogical practices become inclusive as well.”

In Module II, the following contributions are noteworthy:

“Families are the first source of support, the first group where the inclusion occurs. For many persons with disabilities, the family support serves as a bridge to have access to other forms of assistance necessary to fully enjoy human rights.

Supports not only eliminate barriers; but allow for the fulfilling of the rights of all persons with disabilities. Therefore, reasonable adjustments are made that are specific measures implemented in order to modify and adapt the environment, goods and services to particular needs.”

“Families' empowerment is the first factor of success in inclusive education; but that does not mean that it is the easiest to achieve. Empowering the family means sharing power much more than sharing knowledge and information!

Supports collaboration for the elimination of social and environmental barriers to enable dignity, autonomy and independence of people with disabilities. That is, this allows the person with disabilities to make decisions, communicate their choices; and among others, participate fully in different contexts: home, educational, labor and social.

On the other hand, not only do people with disabilities need such support, but WE ALL need some kind of support in the course of life when facing a hardship.

As a synthesis, it is not the students who must adapt to the school, but rather the schools that must produce as many modifications as necessary to ensure that all students receive educational experiences and access to what is defined as “Common” in curricular design. “

In Module III, the following contributions and reflections are noteworthy.

“Human beings must communicate to be free to integrate into society. Since we are born (although we do not have the ability to speak) we communicate

through our emotions and expressions such as screams, smiles, tears. Throughout life we use appropriate language for ourselves.

Some people with disabilities for various reasons can have challenges to achieve the full development of language and communication. However, the barrier in being able to communicate with a student who has a disability is not precisely their condition. What is necessary is an interlocutor who is willing to listen to the ways the student manifests themselves. It is necessary to establish an emotional bond to be able to interact, to be really interested in what they are trying to transmit to us. If that is accomplished, they will be able to express their messages.

So, in order to promote language development, it is extremely important to provide students with disabilities and complex communication needs with the necessary tools to communicate their wishes and interests. In this sense, the possibility of generating pictograms to facilitate their choice and to use assistive technologies is an important aspect that we as a teacher must generate and develop.”

In Module IV, several contributions that were made that are summarized in the text below:

“The benefits of calendar systems for students with complex communication needs include the ability to communicate, anticipate, and decide. The student has the opportunity to know what activity he / she will perform, as well as to remember which ones have already finished. Also, it allows for the establishment of routines and a greater organization for those students who need it. In addition, it facilitates communication because it offers topics to talk about, increasing social interaction.

On the other hand, it is important when designing a calendar, to establish what is the objective that must be met. Also, it must be taken into account the materials to be used; given that they must be long lasting, call the student's attention, and be touchable, fragrant, observable. That is to say, that the student be able to understand what we want to transmit to him. Finally, it must be enjoyable while using it.”

“In my professional practice the use of a System of Calendars was, in the beginning, a challenge. I needed to change the work structures of my initial formation and to move into a new model of teaching and learning. A calendar facilitates communication. Our students understand more and better when we add

objects or images to words to facilitate receptive and expressive communication. For example, a student calmed down her anxiety and was motivated when the Activity Calendar informed her of the morning's activities; her face relaxed and she expressed herself nodding with a smile for what was about to come. She also stopped sleeping in the classroom, and stopped crying at the end of an activity, as soon as she was told by the calendar that 'YES, the activity finished but another activity was next', and she 'could see' that other activity".

"In another situation, a student could make choices for daily activities, and the design and structure of the calendar routine supported the dialogue. With respect to time, the concepts of future and past were expanded. Emotionally, it provided security because the student understood what was planned for a whole day and changes in the routine could be anticipated, so the student could get prepared. We began with photographs of our own meals and utensils. I remember the day I finished putting them together. It occurred to me to give them to the student, so he could get to know them. It was very shocking as he looked at the photos and compared with the real things he had on the table. Immediately he gave me the juice photograph. Eureka!!!! He was communicating! From then on, hits ended, the meal calendar went out for a walk along with us for a long time.

On the other hand, the incorporation of calendars was something new and positive for the parents. In some cases, it could be extended to the home and in others it could not. The parents were able to observe how their children responded and how their participation was due to the implementation of this system. It can be seen that a calendar not only favors the student with a disability but also their environment. It requires flexibility and people must be open minded to change paradigms and perspectives. It is a slow process, but with great aspirations."

In Module V, when developing the content on the Collaborative Process in the elaboration of the Individual Educational Program (IEP), the participants expressed, among other ideas, those that are transcribed below:

"The process of preparation of the Individual Educational Program (IEP) must be collaborative, where a fundamental aspect is for the students and their people close by to define what needs they have and in what way they are going to be addressed during the educational program. By doing it in this

cooperative and collaborative way, and focusing on the student, we give prominence and decision on their own learning. We also include the wishes and needs of the family and / or caregivers. Professors and specialists contribute from their own subjects the contents and strategies agreed with the other participants of the IEP."

The IEP must be devised, organized, designed and implemented with clear purposes and objectives for the short term and projected into the future.

"At all levels of schooling, the student with disabilities should have the opportunity to access all curricular spaces: languages, physical education, mathematical logic, language practices, among others. Given that there is no specific model, the student will require meeting spaces, planning, evaluation and re-elaboration.

The IEP is a tool for planning and systematizing the dynamic agreements between a student, his family and his teachers in order to guarantee the educational conditions that each student needs, which does not include content or time reduction."

"The preparation of the IEP for a Collaborative Team is a challenge that requires us to unlearn and relearn new ways of working together with others with the student at the center. It involves finding a fair balance between the recognition of rights, what is desirable and what is possible. Finally, institutional management will play a fundamental role in order to enable time and physical spaces to build collaborative work upon. "

In Module VI, the following contributions and reflections were highlighted.

"Curricular alignment is the right of our students to access the general curriculum to favor their full inclusion first in school and then in society. This alignment is achieved through the IEP which works as a bridge between the student and the regular curriculum. To align, we must provide and ensure the necessary support to guarantee access to the contents. Curricular alignment can mean modifying strategies, simplifying activities, re-organizing information and contents, to make our classes accessible according to the student's potential and capabilities."

"We must have a more democratic school where diversity is understood as a starting point for positive constructions so that we all have the possibility of

integrating ourselves into the educational system. For this, it is necessary to understand that learning is a right and that it is our responsibility to deliver the contents in an accessible way for all by offering the necessary supports. The curriculum must be made significant by planning for all students in the class where the uniqueness of each one is considered, by setting objectives with expanded aims, by organizing a common curriculum as a frame of reference and contexts, meanwhile considering the prior knowledge, interests and abilities of each student."

This will be possible through collaborative work between the student, his family and professionals.

b. Tutor's and Coordinator's Thoughts

We have selected some aspects / indicators that have been successful according to participants.

- The training offered an opportunity to share their daily practices and ask questions about them.
- The diversity of participants enabled us to have a great variety of questions, concerns, challenges and comments that enriched not only the rest of their colleagues but the educational proposal in general.
- The challenges for both the tutor and the coordinator was to offer the answer they were needing by responding at the time they required it.
- The theoretical content was novel and there were many stimuli to commit with the diploma.
- Families' participation was important because it allowed the rest of the participants to listen to their needs.
- Daily presence in the classroom (middle platform) is essential to be able to offer not only follow-up but also to make the participants feel accompanied during the education journey.
- Tutor's and coordinator's functions need to be clearly defined to allow not only a better accompaniment to the participants but also support among team members.
- The inclusion of a space for the students to share good practices allowed them to empower themselves and learn from each other through real models that can be lived daily.

Final Remarks

It is noteworthy that the indicators of success of this course have been: the possibility of having participants coming from several regions of Argentina, who play different roles in the educational processes, from supervisors to teachers and parents.

We can also indicate that online training allows an excellent possibility of training. People who live far from urban centers and have difficulties to access in-person continued education programs can participate actively through this modality.

Much more could be said. However, we think that the words of one of the mothers participating in the training could express much more clearly what this Diploma achieved:

"When a child has an adequate IEP and all the team and family is committed to fulfilling what corresponds to each one, having the child in the center, the child can learn the contents sometimes even surprisingly better than their peers. And at the same time, this is a clear example that actually we rarely see such a well-done job as we were taught in this seminar. When the school population is vulnerable due to low social environment and the school does not have resources, it is very difficult to carry out what has been learned here.

With this example, I want to show my fellow professionals of this course how IMPORTANT IT IS FOR EACH CHILD YOUR COMMITMENT AND VOCATION. That is why I take this opportunity to salute you and thank you – from my little place – for the commitment, vocation and professionalism that you have shown in this course we have shared. I salute you and I hope more and more people are like you."

Without a doubt, the words expressed by the participants motivate us to reflect on the possibility of replicating this diploma to ensure that more students are included in their families, schools and community.



María Aparecida Cormedi, PhD
mcormedi@gmail.com



Graciela Ferioli, MA
g_ferioli2000@yahoo.com.ar

Developing an Engaging Online Experience for Participants of Perkins International Academy Courses in Latin American and the Caribbean

Alvaro Diaz (Monitoring, Evaluation and Learning Officer); Paige Klotzman (Monitoring, Evaluation and Learning Officer); Gloria Rodriguez-Gil (LA&C Regional Director)

Introduction

Since 2009 Perkins International’s Latin America and the Caribbean¹ (LA&C) program has worked with governments, universities, and peer organizations to deliver online courses throughout the region, covering topics such as early education, visual stimulation, adaptive design, multiple disability, and transition to adult life.

As part of a new global strategy, Perkins International (PI) launched the PI Academy Foundations Course in 2016, a certified course that provides an international competency standard for teachers and service providers of children with multiple disabilities and sensory loss. The Course consists of 4 modules on the topics of Learners with Multiple Disabilities and Visual Impairment, Communication, Assessment, and Curriculum.

The LA&C Region delivered the first online Foundations Course starting August 2016 in Argentina. The Course is delivered over 5 months for a total of 120 instruction hours (compared to the in-person version delivered over 2 weeks for 75 instruction hours) and is asynchronous: students log onto a course website on their own time to watch videos, complete assignments, and participate in forums. Participants are graded according to their participation, the completion of a portfolio, and exams, and must meet minimum requirements in these areas to receive a PI Academy certificate.

Between July and November 2017, three more online courses began in Argentina, Ecuador, and Mexico, which included participants from seven Latin American countries. Despite having over seven years of experience in delivering online courses, PI LAC&C staff realized that some changes were necessary to improve delivery of the course and ensure successful participant completion since some participant attrition was noted during the first two course deliveries. In order to ensure a high-quality delivery of the Foundations Course, an overall process of evaluation was carried out, consisting of a

literature review, a review of participant and instructor evaluations, interviews, and analysis. Through this process, PI has collected evidence of good practices that allow both instructors and students to have valuable teaching and learning experiences.

Online Instruction

Through the literature review, the relevance of online learning in the Region was confirmed, as Latin American universities have seen a considerable rise in demand for e-learning programs (OECD 2015). With convenience and flexibility being key drivers of deciding to choose an online education (Aman, 2009; Jaggars, 2014), it seemed a fitting environment for PI Academy participants who are typically full-time professionals.

Although 80 % of the LA&C region reside in urban areas (World Bank, 2018), the population is still more sparse compared to the world average (World Bank, 2017) with a population of more than 620 million living in 22 million km² distributed across 20 countries. These characteristics may help to visualize why providing the option of online learning is an appropriate strategy to deliver specialized training to those located outside cities and cut down on travel costs.

Still, there are challenges to acknowledge in online learning. Learners must have consistent and reliable access to the internet; unfortunately for many learners in LA&C, access to internet can be limited (M. L. Neri de Troconis and Rocha, personal communication, 2018). Students may find the interactions of online courses to be less personal, or feel they are teaching themselves, whereas traditional courses offer the possibility to seek immediate attention from the instructor and participate in peer interaction (Jaggars, 2014; “The Trouble with Online,” 2013). To combat some of these negative experiences, the literature underscored the importance of creating an online community; maintaining structure



Alvaro Diaz



Paige Klotzman



Gloria Rodriguez-Gil

and organization; encouraging active participation of students; and establishing a presence of the online instructor. Such factors were considered throughout the evaluation process.

Looking to Improve PI Academy Online Courses

Evaluations are part of the strategy PI established to have reliable information for decision-making and improving the quality of trainings. Participants and instructors of the Foundations Course are encouraged to complete an end-of-course evaluation. An initial review of the course evaluations revealed a need to address organization and presentation; technology use and access; and participant engagement and motivation.

In particular, participants struggled with the online platform. For some, the PI Academy course was their

first online learning experience and it lacked necessary orientation resources. In an online environment, we found that participants needed additional support to encourage them to dive deeper into forum discussions and interact collaboratively with their online counterparts.

The LA&C Regional Team made changes based on the evaluations results. The process of revision carried out by PI can be seen in Image 1.

The course organization and presentation was improved by reorganized layout and content; adding a week-long introductory module; and maintaining a consistent presentation and organization throughout. Clearly defined roles and responsibilities of instructors, participants, web technicians, and course coordinator were established.

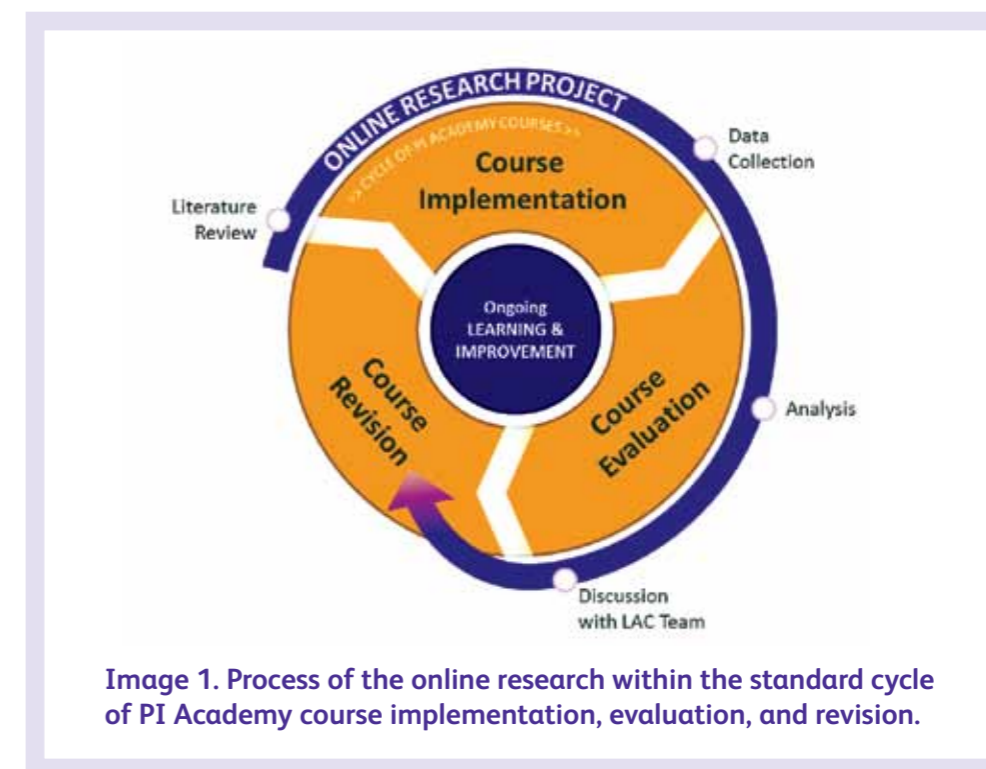


Image 1. Process of the online research within the standard cycle of PI Academy course implementation, evaluation, and revision.

¹ Perkins Latin America and the Caribbean Office (www.perkins.org/international/latin-america) is a small corporate member of DbI

Table 1. Timing of participant attrition by course.

Course	Originally Enrolled	Drop out during Module 1	Drop out during M2	Total Deserted out of Enrolled
Cohort 1	16	4	–	4 (≅ 25 %)
Cohort 2	36	14	2	16 (≅ 44 %)
Cohort 3	25	1	1	2 (≅ 8 %)
Cohort 4	21	3	–	3 (≅ 14 %)
TOTAL	98	22	3	25 (≅ 26 %)

Results of Changes

Regarding participant attrition of the first four cohorts (see Table 1), the main reasons given by participants to discontinue the course included lack of resources (either money or time); unreliable internet connection; lack of capacity to work online; misconception of course topics, resulting in unmet expectations; and health problems. Overall, the first two cohorts saw a higher proportion of participants who withdrew from the course especially during module 1 (22 out of 25 who had dropped out, but only 3 participants during module 2). Several possible factors of attrition were assessed, such as: professional background, geography, changes in the course structure (the order of modules delivered), and tuition costs.

Of these factors, the only one considered to have a significant impact on participants' completion of the course has been the initial financial investment by participants. Participants from the first 2 Cohorts had the option to pay by installments throughout the course while the last 2 Cohorts were required to pay up front in full.

To closely monitor newly implemented changes, the third and fourth cohorts were given an additional

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A lack of negative comments about the structure and usability of the online platform indicate that the platform was greatly improved.
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midpoint evaluation. Responses from instructors and course coordinator to the midpoint evaluation indicate that the introductory module was highly beneficial for participants, especially given that many have little technical experience or no experience with online learning platforms. Some benefits were: easier access to the course schedule, list of assignments and other due dates. Besides, course coordinators and early module instructors met expectations by providing individual and group guidance, as well as individual follow up, promptly responding to participants' questions. Instructors implemented more strategies to encourage active forum discussions and address any content that needed to be clarified.

In the final end-of-course evaluations, participants expressed that the course was interesting and enriching. The support and partnership of the course coordinator was mentioned as a successful element of the course. Instructors found value in and made use of the personal communication messaging system to maintain contact with the participants. They observed that the participants were active in the online forums. Amongst the participants, there was a mix of comments about the instructors' responsiveness and quality of responses provided and it appeared that expectations and guidelines were not made clear.

Overall, the difference in comments from the first two cohorts to the second two cohorts reveal that the editing of the online platform was largely beneficial in creating a more navigable and user-friendly online learning environment. A lack of negative comments about the structure and usability of the online platform indicate that the platform was greatly improved. Still, there is room for improvement in the instructor-participant interactions to provide further support to participants.

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The analysis indicates that incorporated changes thus far have been helpful for dissuading participants from deserting the course.
 ”

Conclusions

Through this intensive evaluation process, we have found that conscientious efforts must be made to enable a productive and supportive online environment for participants of PI Academy online courses. Extraordinary attention must be given to the beginning of the course so that participants become comfortable working in an online environment. Efforts should not be solely directed toward course content but must be extremely focused on how the course is delivered. Particularly, we have found that the roles of the instructors, course coordinator, and webmaster are critical for effective delivery of the online course; therefore, it is important that each actor meets the expectations outlined in their roles and responsibilities. Administrative factors, such as the payment schedule of the course, are important to consider as well.

The analysis indicates that incorporated changes thus far have been helpful for dissuading participants from deserting the course. Adjustments to the course were made in response to the participant and instructor evaluations; therefore, continuing the monitoring and evaluation process is paramount as PI seeks to improve its online courses. Continual monitoring is also important because results may reveal that what works well in one delivery may not be appropriate in another context – something that must be considered as the Region has started implementing blended courses. Monitoring the courses in this manner will allow us to collect more data, which will make predictions and future planning more reliable.

Continuous evaluations involving PI staff, instructors and participants involved in course delivery have been invaluable for improving the online PI Academy courses and establishing online practices that will guide the course in reaching higher standards in online learning. As different points of view and varying perspectives have informed the evaluation and enriched our knowledge about the course, so too it is in the essence of PI Academy to share our experience with key stakeholders.

For more information, contact Gloria Rodriguez-Gil (gloria.rodriguez@perkins.org)

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Sharon Barry Grassick (1950–2018)

After a very lengthy struggle with cancer, Sharon Barrey Grassick, aged 68, passed away August 25th, 2018 in the Bethesda Hospice at Claremont, Western Australia, surrounded by her close friends and Rob, her much loved son.

Sharon (Sha to her close friends) was widely regarded as Australia's leading teacher and researcher in the complex area of communication skills for children and adults who are Deafblind. She was author of a number of major journal articles, substantial training manuals and specialist videos as well as a presenter at numerous national and international conferences on deafblindness and CHARGE Syndrome. Sharon was instrumental in establishing the Western Australian Deafblind Association (WADBA) and headed that organisation for many years before it amalgamated in 2001 with the Royal WA Institute for the Blind to become Senses Foundation.

Originally from Upstate New York, Sharon was awarded a M.Sc. in Deaf Education in 1973 from the State University of New York at Geneseo. She was recipient of a Rotary International Award (1980), to study at Sydney's Macquarie University as Research Assistant at North Rocks Deaf and Blind Children's Centre. Here she developed a passion for building communication with children who are deafblind. She was initially a classroom teacher, then visiting teacher, university lecturer and coordinator of services for individuals with deafblindness. She also taught the Deafblind Communication modules in the Auslan Studies Course at TAFE and was Team Leader of the Deafblind Education Service based at WA Institute for Deaf Education (WAIDE) as well as Adjunct Lecturer in Sensory and Multiple Disability at the RIDBC Renwick Centre, North Rocks, NSW.

She was as well, Secretary of the Australian DeafBlind Council (ADBC) and WA Director of the CHARGE Syndrome Association of Australasia. Sharon presented at numerous forums nationally and internationally and was Scientific Committee Chairperson for the 14th World Conference of DbI (Deafblind International) held in Western Australia in 2007.



Stan Munroe (1944–2019)

On Monday February 11th, 2019 we lost a dear friend, colleague and the editor of this magazine Stan Munroe of Canada, as the result of a stroke.

Stan obtained his Master's in biology from the University of New Brunswick and was a wildlife biologist with the Ministry of Natural Resources until his retirement in 1997. Once retired Stan began a second career with the Canadian Deafblind Association (CDBA) using his skills to lead projects, organize events and represent CDBA on the DbI Board.

He was a strong supporter of CDBA and Deafblind International (DbI) following the birth of his oldest son Andrew, who was deafblind as a result of congenital rubella syndrome. His work with and dedication to CDBA spanned a lifetime. He has sat on the DbI Management Committee as the Information Officer for the past eight years.

Stan embraced each of his roles in our field with commitment and unwavering determination to advocate for persons who were deafblind. He was especially proud of his work to inform and empower family members, both across Canada and around the world. He often referred to his role as editor of DbI Review as a "labour of love", as it afforded him the opportunity to interact with so many wonderful people. He was respected by all who knew him as positive, kind, hard working and fun loving. We will be forever grateful for his contribution to our field both personally and professionally.

Our thoughts and prayers are with his wife Carol and his children Andrew, Jonathan and Sarah.

Carolyn Monaco
CDBA National President, DbI ManCom – Strategic Planning Officer

DbI Review: "a labour of love"
– Stan Munroe

Get visual descriptions on your back without being interrupted

The Danish DeafBlind Association is proud to present a new book and free app with 139 haptic signals used for visual descriptions for deafblind people:

Haptic signals - 139 new and known signals

Download the app or pdf for free!

Download the book in a free pdf-version here: www.fddb.dk

(also attached here in a pdf and text version)

Download the app for free – for Android and Apple. Find it where you find your apps.

The book price: 20 euros

(was sold at the WFDB world conference for deafblind people in Spain in June).

Contact Fddb at fddb@fddb.dk if you wish to buy the printed book

What is haptic signals?

With a system of haptic signals made on the back, shoulder, arm or hand, deafblind people can get information that other people get visually without being interrupted in an ongoing conversation.

Is somebody smiling?

Are people leaving the room?

What shape does the room have?

Is dinner being served, while I am talking..?

This is all information that can be given discretely through a touchable system of simple signals, shapes and symbols made on the back, shoulder, arm or hand.

Who developed the 139 haptic signals?

The signals have been developed by deafblind persons and interpreters in Denmark. We now hope to inspire deafblind people, interpreters and relatives all over the world to learn haptic signals to give deafblinds a much more adequate visual description of what is going on – while it is going on!

**We want to inspire deafblind people all over the world
to adapt the system to their own language**



The app and book: **Haptic Signals** can be used to study the 139 signals on your own or along with an interpreter, and we hope to inspire organizations all over the world to adapt the signals to their own language and communication habits.

Approximately 50% of the Danish signals are inspired by the equivalent sign for the word in Danish sign language. To make it easier to remember for your national deafblind members, we suggest, you develop you own signals – you are welcome to use as many of the symbolic signals as you like from the Danish system!

It is our hope that the use of haptic signals will become a natural element within visual interpretation to all deafblind persons.

**Download the app for free – for Android and Apple.
Find it where you find your apps.**

Spread the news

Please, spread the news on all your news channels and forward this email to everybody who might be interested in haptic signals.

Danish deafblind persons say about using haptic signals:

"I can now participate socially, when I meet people. Before I never knew when to speak or when to smile."

"I never want to attend in any meeting again, without getting haptic signals on my back."

For more information, please contact:

Pia Hesse

Head of Communication

The Danish DeafBlind Association



pia@fddb.dk

www.fddb.dk

Facebook: Haptic Signals

DbI Board Membership 2015–2019

Management Committee

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



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



Bernadette Kappen
Vice-President
The New York Institute
for Special Education
USA
(bkappen@nyise.org)



Frank Kat
Vice-President
NETHERLANDS
(F.Kat@outlook.com)



William Green
Immediate Past President
AUSTRIA
(green.lfo@usa.net)



Gary Daly
Secretary
Able Australia
AUSTRALIA
(gary.daly@ableaustralia.org.au)



Maria Brons
Joint Treasurer
Kentalis
NETHERLANDS
(m.brons@kentalis.nl)



Knut Johansen
Development Officer
Signo Vivo
NORWAY
(knut.johansen@signo.no)



Carolyn Monaco
Strategic Planning Officer
Canadian Deafblind Association
CANADA
(carolyn.monaco@sympatico.ca)



Trees van Nunen-Schrauwen
Joint Treasurer / Network
Coordinator
Kentalis
NETHERLANDS
(t.vanNunen@kentalis.nl)

Board Observers

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

**International Council for Education
of People with Visual Impairment**
Frances Gentle
(frances.gentle@ridbc.org.au)
www.icevi.org

World Federation of the Deafblind
Geir Jensen
(geir.jensen@fndb.no)
www.wfdb.eu

Representing Large Corporate Members



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



Eugenio Romero Rey
ONCE
SPAIN
(err@once.es)



Maria Brons
Kentalis
NETHERLANDS
(m.brons@kentalis.nl)



Kate MacRae
Able Australia
AUSTRALIA
(kate.macrae@ableaustralia.org.au)



Lena Goransson
National Resource
Centre for
Deafblindness
SWEDEN
(lena.goransson@nkadb.se)



Sascha Wiese
German Deafblind
Consortium
GERMANY
(wiese@stiftungsverbund.de)



Marianne Riggio
Perkins International
USA
(marianne.riggio@perkins.org)



Sian Tesni
CBM (Christoffel
Blindenmission)
UK
(sian.tesni@cbm.org.uk)



**Roxanna
Spruyt-Rocks**
DeafBlind
Ontario Services
CANADA
(ceo@deafblindontario.com)



Rossano Bartoli
Lega del Filo
d'Oro
ITALY
(info@legadelfilodoro.it)



Cathy Proll
Sensity
CANADA
(cproll@sensity.ca)

Representing DbI Networks



Mads Kopperholdt
Adaptive Physical
Activity Network
DENMARK
mads.kopperholdt@rn.dk



Emily Walters
Creative Arts Network
AUSTRALIA
emily.walters@ableaustralia.org.au



Joe Gibson
Outdoor Network
NORWAY
(deafblindoutdoors@gmail.com)



Andrea Wanka
CHARGE Network
Stiftung St. Franziskus,
Heiligenbronn
GERMANY
(aw@andrea-wanka.de)



Ricard Lopez
European
Deafblind Network
SPAIN
(fecoco@fecoco.org)



Emma Boswell
Usher Network
UK
(Emma.Boswell@sense.org.uk)



Simon Allison
Youth Network
UK
(simon.allison@sense.org.uk)

Representing Small Corporate Members



Carolyn Monaco
Canadian Deafblind Association
CANADA
(carolyn.monaco@sympatico.ca)



Marleen Janssen
University of Groningen
NETHERLANDS
(h.j.m.janssen@rug.nl)



Ricard Lopez
Spanish Federation of Deafblindness (FESOCE)
SPAIN
(rlopez@sordoceguera.com; fesoce@fesoce.org)



Gloria Rodriguez-Gil
Latin America and the Caribbean Perkins International
ARGENTINA
(gloria.rodriguez@perkins.org)



Jackie Brennan
Overbrook School for the Blind
USA
(jackie@obs.org)



Ursula Heinemann
Österreichs Hilfswerk für Taubblinde
AUSTRIA
(ursiheinemann@usa.net)



David Murray
Deafblind Australia
AUSTRALIA
(david.murray@deafblind.org.au)



Knut Johansen
Signo Døvblindesenter
NORWAY
(knut.johansen@signo.no)



Bernadette Kappen
The New York Institute for Special Education
USA
(bkappen@nyise.org)



Lars Sobje
Center for Deafblindness and Hearing Loss
DENMARK
(laejs@rn.dk)



Koh Poh Kwang
Lighthouse School
SINGAPORE
(kohpohkwang@lighthouse.edu.sg)



Marie-Jose vandenDriessche
Royal Dutch Visio
NETHERLANDS
(MarieJosevan denDriessche@visio.org)



Matthew Wittorff
Senses Australia
AUSTRALIA
(matthew.wittorff@senses.org.au)



Maria Creutz
Nordic Centre for Welfare and Social Issues
SWEDEN
(maria.creutz@nordicwelfare.org)



Mirko Baur
Tanne, Stiftung für Taubblinde
SWITZERLAND
(mirko.baur@tanne.ch)

Forsight Australia
AUSTRALIA
(forsight@forsight.net.au)



Lena Goransson
National Resource Centre for Deafblindness
SWEDEN
(lena.goransson@nkcd.se)

Secretariat News



Dear Members,

Since my last report Deafblind International (DbI) ManCom met recently in Moscow, Russia with the DbI Board meeting in Moscow, Russia. While in Russia we attended the 1st International Young Researchers Conference on Deafblindness. This conference was an enormous success and congratulations go to the organising committee for presenting outstanding programs.

Our DbI membership has increased since the DbI America's conference in April 2018. We promoted the DbI membership and the 17th DbI World Conference in Australia. 14 new DbI individual memberships were signed up. Currently membership includes: 14 large corporates, 50 small corporates and 167 individual memberships. Some memberships are outstanding but we have a better follow up system in place now.

During the year I worked with the DbI Treasury in The Netherlands as we had the new software programs, TeamLeader and Twinfield set up. We now have new DbI ManCom members from Kentalis as our Treasury with Maria Brons and Trees

Schrauwen ev van Nunen from the DbI Treasury and Peter Drijfhamer as their Treasury Assistant.

Can I please ask that if you have any change of personal membership details that you contact me on secretariat@deafblindinternational.org so that we can keep our new database up to date.



Gary Daly

Gary Daly, DbI Secretary
Gary.Daly@ableaustralia.org.au

YOU CAN CONTACT THE DBI SECRETARIAT AT:

secretariat@deafblindinternational.org if you require your contact details to be updated or have a membership invoice to be resent.

Via the Networks on the website:
www.deafblindinternational.org/networks.html

www.facebook.com/dbiint

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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

DbI Review – Sponsorship Guidelines

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



Deafblind
International DbI

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

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

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

Applying for Sponsorship of an Edition of the DbI Review

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

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

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

Sponsorship Levels, Costs and Entitlements of DbI Review

Level 1 Sponsorship = 8000 Euro

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

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

Level 2 Sponsorship = 4000 Euro

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

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

Level 3 Sponsorship = 2000 Euro

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

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

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



Honorary Officers

President

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

Vice-President

Bernadette Kappen
The New York Institute for Special Education
Email: bkappen@nyise.org

Vice-President

Frank Kat
Royal Dutch Kentalis
Email: F.Kat@outlook.com

Immediate Past President

William Green
Email: green.lfo@usa.net

Treasury

Maria Brons & Trees van Nunen-Schrauwen
Email: mbrons@kentalis.nl

Secretary

Gary Daly
Able Australia
Email: gary.daly@ableaustralia.org.au

Strategic Plan Officer

Carolyn Monaco
Canadian Deafblind Association
Email: carolyn.monaco@sympatico.ca

Development Officer

Knut Johansen
Signo
Email: knut.johansen@signo.no

Networks

Acquired Deafblind Network

Liz Duncan
Email: lizduncan64@yahoo.co.uk
Website: http://adbn.deafblindinternational.org

Adapted Physical Activity or APA Network

Mads Kopperholdt & Anders Rundt
Emails: mads.kopperfeldt@rn.dk; anmaru@rn.dk

CHARGE Network

Andrea Wanka
Email: aw@andrea-wanka.de
Website: http://chargenetwork.deafblindinternational.org

Communication Network

Marleen Janssen
Email: h.j.m.janssen@rug.nl
Website: http://communication.deafblindinternational.org

Creative Arts Network

Emily Walters
Email: emily.walters@ableaustralia.org.au
Website: http://creativearts.deafblindinternational.org

EDbN

Ricard Lopez Manzano
Email: rlopez@edbn.org
Website: http://edbn.deafblindinternational.org

Ibero Latin American Network

Vula Ikonomidis
Email: vula2004@hotmail.com
Website: http://iberolatinamerican.deafblindinternational.org

Network of the Americas

Marianne Riggio
Email: Marianne.Riggio@Perkins.org
Website: http://americas.deafblindinternational.org

Outdoor Network

Joe Gibson
Email: deafblindoutdoors@gmail.com
Website: http://outdoornetwork.deafblindinternational.org

Research Network

Walter Wittich
Email: walter.wittich@umontreal.ca
Website: http://research.deafblindinternational.org

Rubella Network

Nigel Turner
Email: nigel.turner@sense.org.uk
Website: http://rubella.deafblindinternational.org

Social-Haptic Communication Network

Dr. Riitta Lahtinen & Russ Palmer
Email: riitta.lahtinen@cloud.com; rpalmer2@tiscali.co.uk
Website: http://socialhaptic.deafblindinternational.org

Tactile Communication Network

Paul Hart
Email: phart@sensescotland.org.uk
Website: http://tcn.deafblindinternational.org

Usher Network

Emma Boswell
Email: Emma.Boswell@sense.org.uk
Website: http://usher.deafblindinternational.org

Youth Network (DbIYN)

Simon Allison
Email: simon.allison@sense.org.uk
Website: http://dbiyn.deafblindinternational.org

Large Corporate Members

AUSTRALIA

Able Australia
Kate MacRae
Email: kate.macrae@ableaustralia.org.au
Website: www.ableaustralia.org.au

Senses Australia
Matthew Wittorff
Email: matthew.wittorff@senses.org.au
Website: www.senses.org.au

CANADA

DeafBlind Ontario Services
Roxanna Spruyt-Rocks
Email: ceo@deafblindontario.com
Website: www.deafblindontario.com

Sensity
Cathy Prall
Email: cprall@sensity.ca
Website: www.sensity.ca

DENMARK

Interfond
Pierre J. Honoré
Email: pjh.interfond@mail.dk

GERMANY
CBM – Christoffel Blindenmission
Monika Brenes
Email: Monika.Brenes@cbm.org
Website: www.cbm.org

German Consortium AGTB
Sasha Wiese
Email: wiese@stiftungsverbund.de

German Deafblind Consortium
Roland Flaig
Email: roland.flraig@stiftung-st-franziskus.de

ITALY

Legadel Filo d'Oro
Rosanno Bartoli
Email: info@legadelfilodoro.it
Website: www.legadelfilodoro.it

SPAIN

ONCE
Eugenio Romero Rey
Email: err@once.es
Website: www.once.es

SWEDEN

Mo gård
Lena Goransson
Email: lena.goransson@nckdb.se
Website: www.mogard.se

THE NETHERLANDS

Royal Dutch Kentalis
Maria Brons
Email: maria.brons@kentalis.nl
Website: www.kentalis.nl

UNITED KINGDOM

Sense
Gillian Morbey
Email: Gillian.Morbey@sense.org.uk
Website: www.sense.org.uk

USA

Perkins International
Marianne Riggio
Email: Marianne.riggio@perkins.org
Website: www.perkins.org

ARGENTINA

Latin America and Caribbean Perkins International
Gloria Rodriguez-Gil
Email: gloria.rodriguez@perkins.org

AUSTRALIA

Deafblind Australia
David Murray
Email: info@deafblind.org.au
Website: www.deafblind.org.au

Forsight Australia

Forsight Australia
Email: forsight.aus@forsight.net.au
Website: www.forsightaustralia.org.au

AUSTRIA

Österreichs Hilfswerk für Taubblinde
Christa Heinemann
Email: c.heinemann@zentrale.oehbt.at
Website: www.oehbt.at

CANADA

CDBA National
Carolyn Monaco
Email: carolyn.monaco@sympatico.ca
Website: www.cdbanational.com

Canadian Helen Keller Centre

Jennifer Robbins
Email: jrobbins@chks.org
Website: chks.org

The Lions McInnes House – Group Home for Deafblind Persons

Laurie Marissen
Email: LionsMcInnesHouse@rogers.com

Canadian National Institute for the Blind (CNIB)

Sherry Grabowski@cnib.ca
Website: www.cnib.ca

CHINA HONG KONG

Resource Centre for the Deafblind
The Hong Kong Society for the Blind
Doreen Mui
Email: doreen.mui@hksb.org.hk
Website: www.hksb.org.hk

CROATIA

Mali dom – Zagreb Darja Udovicic Mahmuljin
Email: darja@malidom.hr
Website: www.malidom.hr

CYPRUS

Pancyprian Organization of the Blind
Christakis Nikolaidis
Email: pot@logos.cy.net

DENMARK

Center for Deaf
Karin Moreau Andersen
Email: kma@cf.dk
Website: www.cfd.dk

Socialstyrelsen

Trine Skov Uldall
Email: tul@socialstyrelsen.dk
Website: www.dovblindfoedt.dk

Danish Parents Association

Vibeke Faurholt
Tel: (45)+98854332
Email: faurholt@mail.tele.dk

The Center For Deafblindness and Hearing Loss (CDH)

Lars Søbye
Email: lsoe@rn.dk
Website: www.dbc.rn.dk

ETHIOPIA

Addis Ababa University
Email: credadm@kentalis.nl

FINLAND

The Finnish Deafblind Association
Sanna Nuutinen
Tel: +358 40 529 3439
+358 40 604 7477
Email: sanna.nuutinen@kuurosokeat.fi
Website: www.kuurosokeat.fi

FRANCE

APSA-CRESAM
Sonja van der Molengraft
Email: centre.res@cresam.org
Website: www.apsa-poitiers.fr

RPSC-ANPSA

Dominique Spriet
Email: presidency@anpsa.fr

GREECE

Hellenic Association of Deafblind "The Heliotrope"
Diamanto-Toula Matsa
Email: diamatso@gmail.com

ICELAND

National Institute for the Blind, Visually Impaired and the Deafblind
Estella D. Björnsdóttir
Email: estella@midstod.is

INDIA

Sense International (India)
Akhil Paul
Email: akhil@senseindia.org
Website: www.senseindia.org

IRELAND

The Anne Sullivan Centre
Grace Kelly Hartnett
Email: gracekellyh@annesullivancentre.ie
Website: www.annesullivan.ie

NEW ZEALAND

Royal New Zealand Foundation for the Blind (RNZFB)
Jill Baldwin
Email: jbalwin@blindfoundation.org.nz
Website: www.rnzfb.org.nz

NICARAGUA

Asociación de Sordociegos de Nicaragua
Mireya Cisne Caceres
E-mail: sordociegosnicaragua@hotmail.com

NORWAY

Signo kompetansesenter
Anne Lise Høydahl
Email: anne.lise.hoydahl@signo.no

Signo Vivo

Knut Johansen
Email: knut.johansen@signo.no
Website: www.signovovblindesenter.no

Eikholt

Roar Meland
Email: roar.meland@eikholt.no
Website: www.eikholt.no

Statped

Bitten Haavik Ikhdahl
Email: Bitten.H.Ikhdahl@statped.no
Website: www.statped.no

National Advisory Unit of deafblindness

Eva Hirsti
Email: eva.hirsti@unn.no

Regional Center for people with deafblindness

Eva Hirsti
Email: eva.hirsti@unn.no

RUSSIA

Deaf-Blind Support Fund "Con-nection"
Dmitry Polikanov
Email: d.polikanov@so-edinenie.org
Website: www.so-edinenie.org

SINGAPORE

Lighthouse School
Koh Poh Kwang
Email: kohpohkwang@lighthouse.edu.sg
Website: www.lighthouse.edu.sg

SPAIN

Federation of Associations of Deafblind People (FASOCIDE)
Francisco Javier Trigueros Molino
Email: international@fasocide.org.es
Website: www.fasocide.org

Spanish Association of Parents of Deafblind People (APASCIDE)

Dolores Romero Chacon
Email: apascide@apascide.org
Website: www.apascide.org

Spanish Federation of Deafblindness (FESOCIE)

Ricard Lopez i Manzano
Email: fesocie@fesocie.org
Website: www.fesocie.org

SWEDEN

National Resource Centre for Deafblindness
Lena Goransson
Email: lena.goransson@nckdb.se
Website: www.nckdb.se

Nordic Welfare Centre

Maria Creutz
Email: nvcdb@nordicwelfare.org
Website: www.nordicwelfare.org

Mini Corporate Members

DENMARK

Dovblindehuset
Email: olw@cdf.dk

ETHIOPIA

Ethiopian National Association of the Deafblind (ENADB)
Roman Mesfin
Email: enadb@ethionet.et

MALAWI

Visual Hearing Impairment Membership Association (VIHEMA Deafblind Malawi)
Ezekiel Kurnwenda
E-Mail: vihema.deafblindmalawi@gmail.com

African Federation of Deafblind (AFDB)

Ezekiel Kurnwenda
Email: afdb.secretariat@gmail.com

UNITED STATES OF AMERICA

The New York Institute for Special Education
Bernadette Kappen
Email: bkappen@nyise.org

Overbrook School for the Blind

Jackie Brennan
Email: jackie@obs.org
Website: www.obs.org

Texas School for the Blind & Visually Impaired – Texas Deafblind Project

Chris Montgomery
Email: chrismontgomery@tsbvi.edu
Website: www.tsbvi.edu/deaf-blind-project

Specialpedagogisla Skolmyndigheten

Mia Martini
Email: mia.martini@spsm.se
Website: http://www.spsm.se

SWITZERLAND

SZB Beratungsstellen für hörschbehinderte und taubblinde Menschen
Mäde Müller
Email: mueller@szb.ch
Website: www.szb.ch

Tanne, Schweizerische Stiftung für Taubblinde

Mirko Baur
Email: mirko.baur@tanne.ch
Website: www.tanne.ch

THE NETHERLANDS

Bartimeus
Betty van Wouw
Email: bwouw@bartimeus.nl
Website: www.bartimeus.nl

Kalorama, Centrum voor doofblinden

Els Peters
Email: e.peters@kalorama.nl
Website: www.kalorama.nl

Koninklyke Visio

Marie-José van den Driessche
Email: MarieJosevandenDriessche@visio.org
Website: www.visio.org

University of Groningen

Marleen Janssen
Email: h.j.m.janssen@rug.nl

UNITED KINGDOM

Sense International
Alison Marshall
Email: alison.marshall@senseinternational.org.uk
Website: www.senseinternational.org

Scene Enterprises CIC

David Sutton
Email: david.sutton@sceneenterprises.org.uk
Website: www.sceneenterprises.org.uk

UNITED STATES OF AMERICA

The New York Institute for Special Education
Bernadette Kappen
Email: bkappen@nyise.org
Website: www.nyise.org

Overbrook School for the Blind

Jackie Brennan
Email: jackie@obs.org
Website: www.obs.org

Texas School for the Blind & Visually Impaired – Texas Deafblind Project

Chris Montgomery
Email: chrismontgomery@tsbvi.edu
Website: www.tsbvi.edu/deaf-blind-project