

DbI REVIEW

THE MAGAZINE
OF DEAFBLIND
INTERNATIONAL



FIND MEANING BY LOSING EVERYTHING

Page 45

Show that you are a part of Dbl!

Dbl is THE point of connection in deafblindness. You are an important part of that! So show it and get yourself one of our new t-shirts. Produced in India in the middle of the global pandemic they are indeed a statement of global collaboration and exchange. And they fulfill the Global Organic Textile Standard (GOTS). Because this is what we are looking for: A sustainable network making a real change worldwide!



The t-shirts are available in two designs and each one of them in two colours. Make your choice between the Dbl Ambassador t-shirt in purple or white and the Dbl t-shirt in Dbl-green and white.

Order NOW for just 10 Euros per piece directly from our shipping partner Tanne, Swiss Foundation for Congenital Deafblindness.



[https://www.tanne.ch/
dbi-merchandise](https://www.tanne.ch/dbi-merchandise)



LOOKING INTO THE FUTURE WITH A RETROSPECTIVE

➔ 3

NEWS

News from the Network Coordinator

➔ 6

Research Network

➔ 7

Usher Network

➔ 8

Communication Network

➔ 9

Technology Network

➔ 12

Updates from Ireland

➔ 13

ANNOUNCEMENTS

Do you Have a Story to Tell?

➔ 15

Raising Awareness about Deafblindness Across the Globe. One Stitch at a Time

➔ 16

Make a Wave from Coast to Coast – National Deafblind Awareness Month in Canada

➔ 18

Symposium: Living through Touch – Smart Haptic Communication for Inclusion, Accessibility and Participation

➔ 19

ARTICLES

How to Become a Bridge, not a Barrier: Building Peer Relationships for a Young Man with Congenital Deafblindness using Multiparty Interactions in the Tactile Modality

➔ 20

Connecting Youth and Adults with Acquired Deafblindness: An Action Research Study to Gain Insights into the Benefits of Age Diversity in Peer-Matching

➔ 25

A European Online Dictionary for Social Haptic Communication

➔ 29

The Applicability of the HELP and BCP Assessment Instruments to Students who are Deafblind

➔ 33

The Experience of Life with Acquired Deafblindness and CI

➔ 37

At Work With Dual Sensory Loss

➔ 41

OPINIONS AND INTERVIEWS

Find Meaning by Losing Everything

→ 45

Memorable Moments in Dbl

→ 53

5 Great Achievements that Should Make Us Proud

→ 58

EXCHANGE OF EXPERIENCE

Tangible Concepts about COVID-19 for Children with Multiple Sensory Visual Disabilities

→ 61

Accessible Virtual Learning for Children with Extensive Support Needs

→ 65

Rise Like the Phoenix

→ 67

Project Pixan-Mexico and Model Programs

→ 69

Deafblindness in Rwanda

→ 72

Online Version of the Deafblindness Master Program in Groningen Creates New Opportunities for Sharing Knowledge

→ 74

NETWORKS AND NETWORK LEADERS

→ 77

Looking into the Future with a Retrospective

Why shall we talk about the past? Isn't the future the one being of interest? Well I have to say that all my current work on trying to develop the quality of our services for people with deafblindness is based on my long history in the field of deafblindness. I am still inspired by the pioneers that found out that deafblindness is a distinct disability and fought for it to be acknowledged. Deafblindness is so rare, that not many people know about it, and at the same time people with deafblindness are so dependent on broad knowledge about the disability. The society can both increase and decrease the limitation, which deafblindness gives to every individual, so it is crucial that it is widely known and understood.



**HENRIETTE
HERMANN
OLESEN**

VICE PRESIDENT
OF DBI



And that is something the past has taught me – it is a daily battle and hard work to get acknowledgement and understanding of deafblindness in the society. To get this, we need to be visible, we

need to work together internationally, and we need to be clear. This is well supported by the solid work of Dbi, and the new vision of Dbi. We want to be the point of connection.

■ A MESSAGE FROM THE VICE PRESIDENT

Visibility is extremely well taken care of by the Communication Committee – that has taken the task to bomb the social media with constant reminding of the community of deafblindness. It is possible to get access to knowledge on our webpage, and we see networks and others sharing their stories and their work on Facebook or Instagram. How do we get this out to the ones, who don't know about deafblindness? Can we help each other to strengthen this task? I think the research network has done a great work to get researchers interested in deafblindness, and this can lead to the improvement of visibility around the world. Also, the latest film *Connecting the Dots* has made deafblindness visible and interesting. We need to take on our creative hats to do more.

International Work in different networks along the way has also given a very important base of knowledge about deafblindness. In the 90's I learned so much of the work of the European Communication Network, turning into the Dbi Communication Network. It was a great producer of materials about deafblindness and conferences, courses and education around the world. I am so thrilled to see it being carried into the future with new engaged people, that is providing us with webinars about the basic knowledge about working with people with deafblindness. I also remember the conferences arranged by the Acquired Deafblind Dbi Network. They were so inspiring because they combined the personal stories with new knowledge. Again, this network is filled with new engaged people, and it is so good to see. There are much more networks that are carrying the torch to develop and spread knowledge on different aspects of deafblindness, and this is so important for all individuals with deafblindness in the world. We cannot do this on our own in our own country – we need to work together, because we are so few.

In the 80's we, people of the Nordic countries, had to seek knowledge overseas. Perkins and Helen Keller Institute helped us on our

way to learn about deafblindness. We were blessed of this international embracement from our American colleagues. This international work is still going on, where strong organizations help new organizations in other countries with their work with deafblindness. Could we do something to strengthen a collaboration between the organizations, that international work does? Also, international exchange programs are carried out to strengthen the good work – to enlighten each other between borders. As far as I know, DeafBlind Ontario Services has this program, and maybe we could do even more of this in the future?

In the past there has been a very strong collaboration between Dbi, and ICEVI, and WFDB. I must say that I see this being strengthened again, but it is important to have it as a focus all the time. At the same time, there is work to be done in order to improve collaboration.

During the past year Dbi has joined a workgroup with people from ISAAC. This was an initiative from Meredith Prain from Australia to try to get much more focus on the needs of support for communication. Right now, the workgroup – now called International Communication Rights Alliance – has formed a letter to a secretary of UNCRPD to improve the expectation of the work around communication in every country. Communication is more than an interpretation at a meeting or a technology. It is necessary to have 24-hour access to communication in your life. It could be performed through personal assistance (it often is) and it could be performed through universal designs. It could be done through many things. The importance is to get the countries to be more aware of this aspect – that is so essential, but often so invisible for people, because that is just something, that is a part of everything – if you can see, hear, speak. Therefore, we need to improve the expectations of describing the work of communication according to UNCRPD. The working group has sent a letter out for endorsement to all of our members.

We Need to be Clear all the time. Deafblind is very difficult to understand for many people. Why is it unique? – they ask. We must never take for granted, that it is easy to understand. We are the advocates of this status, which is a distinct disability. We have a responsibility to explain over and over again – because if we don't, we will see the acknowledgment disappear very fast. This is what the past has taught me – we have to

be clear and we have to tell it over and over again. Deafblindness is a distinct disability, that needs special knowledge and special support.

This we can do together. Dbl has an important task in all these things. But Dbl is nothing without the members, the networks, the committees, and the Board. Therefore, it is great to see the list of members increasing. Together we are stronger and wiser.

News from the Network Coordinator

**TREES VAN
NUNEN**

DBI NETWORK
COORDINATOR

[T.VANNUNEN@
KENTALIS.NL](mailto:T.VANNUNEN@KENTALIS.NL)

Despite the ongoing pandemic we find ourselves in, the Dbl networks remain active. Through our on-line meetings and active use of social media, we maintain contact with each other in these difficult times.

In the past period a lot has happened in the field of networks. First of all, I would like to invite everyone to look through the Dbl website on a regular basis. If you want to know more about the history of the networks and why are the networks considered so important, watch the video clip that was recently made. In this video clip you can listen to a conversation between the President of Dbl (Frank Kat), the Vice President (Mirko Baur), and me.

We have also started to give the various networks the opportunity to present themselves on the website in Network of the Month. The network leaders of the Ibero Latin America Network and the Youth Network were the first to introduce their networks by means of video clips. Other network leaders will follow it in the coming months.

In addition, we also challenge everyone to participate in the Dbl network contest. In short: enough reasons to read the Dbl website regularly because a lot happens here.

Because Dbl attaches so much importance to the networks, a budget that each network can use has been released. Network leaders can apply for this funding if there are specific activities, publications or events they would like to be involved in. I am pleased to note that various networks have made use of this in the past period.

Finally, the number of new Dbl members continues to grow and with it the members of the various networks. I can therefore only conclude that the Dbl networks are more vibrant than ever!

Research Network

RESEARCH
NETWORK TEAM

The Dbl Research Network is well into its 7th year of existence, and we continue to grow and expand. As of February 2021, we now have 175 members on our e-mail contact list.

Saskia Damen and Flemming Ask Larsen continue the maintenance of the Deafblind International Research Network – [Facebook Group](#), currently at over 1,300 members and growing. Come look us up and join in the conversation! Christine Lehane continues to maintain our Deafblind International Research Network [LinkedIn group](#), currently with 93 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 Dbl Research Network, in case you have an idea you would like to share.

You may remember that the 1st Dbl webinar was held on ZOOM on June 22-26, 2020 around the theme: Living with Deafblindness in a New Reality. The webinar was specifically focused on facilitating independence, participation, and quality of life for persons living with deafblindness. We are very excited to report that the resulting manuscript was recently

accepted for publication, and will be available as an open-access article with the [British Journal for Visual Impairment](#). Look for it in the coming weeks!

In case you missed it, the recordings of 25 of these presentations are available on the [webinar tab](#) of the conference web page of the Deafblind International website.

The current leadership team of the Research Network is composed of:

- [Prof. Dr. Walter Wittich](#), Canada (Chair)
- [Dr. Saskia Damen](#), the Netherlands (Deputy)
- [Prof. Dr. Marleen Janssen](#), the Netherlands (Core Member)
- [Dr. Meredith Prain](#), Australia (Core Member)
- [Dr. Alana Roy](#), Australia (Core Member)

Please feel free to contact anyone of us if you have any ideas, 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.

Usher Network

EMMA BOSWELL

USHER SERVICE,
NATIONAL USHER
COORDINATOR

EMMA.BOSWELL@SENSE.ORG.UK

First of all, the Dbl Usher Network Committee has updated our web pages following recent Dbl guideline changes.

Then, no one can deny the pandemic has changed the world in the last 12 months, but for none of us it has changed as much as for the deafblind community. We have woken up in a new world where touch is forbidden and our faces are covered, which leads to huge barriers to communication. However, I was amazed to see how Usher communities all over the world have adapted and embraced this new world. They have learned new technologies with a moment's notice and have familiarised themselves with new platforms and ways of working and living. They have adapted and got used to the New Normal to the best possible extent they can, and even started finding positive aspects where they can despite the challenges of COVID-19.

The mainstream world underestimated what a world without touch would be like. Many people are now saying what the deafblind world knew all along, a life without touch feels like no life at all. Touch and interactions with human beings are such an important part of the deafblind world and I think those around us who have been forced to become touch adverse are realising how isolating and lonely it can be. That is why

I think the pandemic has had a bigger effect on deafblind communities. I have heard from many Usher clients who have caught the virus and have been living without a sense of smell or taste on top of their dual sensory loss or deafblindness.

Also, sadly, there are some deafblind people who are not able to access any technology. We must remember to support these people. This is why I think it is vital to provide choices, not only technological ones but also face-to-face options, is it still much needed for some members of the Usher and deafblind community. The roll-out of vaccination programmes all over the world is important for these deafblind people and those who support them as well as the wider population. It can give us hope that things will be opening up soon. That is why the Usher Network is hopeful we will be successful in applying to hold a 2-day Dbl Usher Network Pre-conference in Canada in 2023. Never before has face-to-face connection felt so important, so needed. We must take stock of how this pandemic has affected and changed our community, and we need to do it together.

Communication Network

Series: Communication Network Webinars and Congenital Deafblindness

The Communication Network hosts a series of three webinars on the themes of social interaction and communication, based on research and on the outline in the series booklets on Communication and Congenital Deafblindness (published by the National Board of Social Services, Denmark and Royal Dutch Kentalis, the Netherlands, 2006, 2007, 2008, 2009), developed by members of this network. This series of webinars is organized on request of the Board of Deafblind International, and it is especially focused on family members and parents of children and adults who are born with deafblindness, or those with limited language (speech or sign) who wish to develop their own communication competences and the competences of their deafblind family member.

There will be three webinars on the same topic run in different time zones. So families can choose the time zone of their region. Each webinar is organized in an interactive form and in each webinar video-analysis plays an important role to see what works well for each interaction.

Video-analysis is focused on improving the strategies of the communication partner, with the aim to improve communicative competencies of a child or adult with deafblindness. Bodily-tactile strategies in communication are emphasized. Video-analysis has been always the core issue since the appearance of this Communication Network in 1989.

We find it essential that also nowadays many people can benefit from the developed knowledge and learn new skills themselves.

These webinars will be held in English, but the language can be adapted depending on the participants in the break out groups. In each webinar, only a few theoretical concepts will be covered. This gives the presenters the possibility to go really in depth and to attune to the needs and questions of the family members. Different presenters will use the same format with own subjective knowledge adapted to different cultural practices. The first webinar will be held in April 2021 (week 17), the second one in November 2021, and the third one in April 2022. We hope this format will be a success so we can continue this series every half a year in the future.

The content of the concepts in each webinar:

Webinar 1: **Social Interaction**

Mutual attention, proximity and making contact, responsive attunement to initiatives and utterances, affect attunement and reciprocity.

Webinar 2: **Meaning Making**

Shared experiences, emergence of gestures, bodily impressions and gestures, joint attention, building up shared meaning, meaning negotiation and naming.

Webinar 3: **Symbolic Communication and Co-construction of Language**

MARLEEN JANSSEN

COMMUNICATION NETWORK LEADER

H.J.M.JANSSEN@RUG.NL

Symbolic communication, mapping linguistic forms and shared life experiences, tactile gestures, signing and hand positioning and co-construction of language in some cases.

The format will be as follows: a webinar takes 3 hours with an alternation between presentations of concepts, discussion of concepts related to everyday life in break out rooms and a plenary discussion in which reflections from the break out rooms are shared.

Of course, we could organize a series of three webinars on each concept, but as we find **communication development** important, we did not want to stay too long in the basic level of attunement and social interaction and give more priority to meaning making, symbolic communication, and language. We know many professionals also want to join this series of webinars but they will only get permission if we don't have enough family members and then first come first served. The presenters for the first webinar, which will be held on April 27-29, 2021 are: for Europe – Saskia Damen, the Netherlands; for Africa – Hellen Shakele, Zambia; for Canada and North America – Rachel Kavanagh; for South America – Maria Aparecida Cormedi, Brasil; for Asia and Australia – Melanie Robertson and Meredith Prain.

Other Activities

Book Overview 40 Years Communication Articles in Dbl Review

Because of the organization of the network and the webinar series, the development of this book takes longer. The good news is that when we publish this book we will also try to publish as many articles in Spanish as possible. I am in contact with Eugenio Romero Rey and we will work together on that.

UG Institute for Deafblindness

All sorts of things happen in Groningen, too. We are engaged in the reorganization of the Master Deafblindness under the leadership of Saskia Damen. As this Master is no longer purely focused on communication, Saskia will report in Dbl Review under separate headings. Also, the alumni activities for this Master will no longer fall under the

Helle Selling Buelund (Center for Deafblindness and Hearing Loss in Denmark) and Meredith Prain (Able Australia) are the facilitators of this program, many thanks to them in advance!

State of the Art Reorganization Communication Network

In the meantime, we are trying to get our network organization in order and that is a lot of work. We have over 140 members by now, and if everything went well they have received an initial email about the series of webinars and a welcome email. We are working on getting a Facebook page, but for now, we can at least communicate with the members. If any individuals have signed up and have not received an email yet, please contact me as something has gone wrong with the email address on the list. Thanks in advance. I had some error messages and will correct that as soon as possible.

If the list is complete then I will work on the organization of smaller networks and find the coordinators for that. It would be great to have reports of the smaller networks in future Dbl Reviews.

Communication Network from now on. Of course, people can stay members of this Communication Network and I will correspond on that later.

About the activities from the UG Institute for Deafblindness I will still report here, because there is much happening in the area of communication. There will also be overlap with the Research Network.

Study Group on Diversity in Communication

This group (Marlene Daelman, Paul Hart, Marleen Janssen, Anne Nafstad, and Jacques Souriau; formerly known as Communication Network) is still very active with education issues in different countries but they also find some time to work on a book on Dialogic Communication Analysis. We will keep you informed about that in the near future and I

am in contact with a person who will report on their activities.

Ph.D. defence of Kirsten Wolthuis on June 3 at the University of Groningen

She did her research at Royal Dutch Kentalis and the thesis is entitled as follows: Layered Communication Development. The creation of a model that can describe, monitor and improve intersubjective communication between people with congenital deafblindness and others. Two articles have been already published. Her promoters are Marleen Janssen, Alexander Minnaert, and Gerard Bol. During the defence at 16.15 PM the following people will ask questions: Susan Bruce, Andrea Wanka, Marijn van Dijk, Tim Hartshorne, Wied Ruijssenaars, Mathijs Vervloed, and Eline van Rooij. The defence will be partially held in English. If you want to follow the ceremony, please let me know and I can give you access to the right link.

If you need more information or if you have questions about this network, contact Marleen Janssen (h.j.m.janssen@rug.nl) or Dbl Communication Network team (dbicommunicationnetwork@rug.nl).

Special Issue in Frontiers in Educational Psychology

Twenty articles have been published in Frontiers in Educational Psychology, and Frontiers in Education under the research topic Development, Wellbeing, and Lifelong Learning in Individuals with a Dual Sensory Loss. I am working with Tim Hartshorne and Walter Wittich to turn this into an e-book. That would be an important academic educational e-book purely focused on deafblindness. You can already read the articles under the [link](#).

Series of Books on Deafblindness

With the same editorial team, we are working on a series of books on deafblindness in which many members of Dbl are involved. The book prospectus is written and is now at the publisher. We keep our fingers crossed. As soon as we have news you are the first to learn them.

Technology Network

MIJKJE WORM

[MWORM@
BARTIMEUS.NL](mailto:mworm@bartimeus.nl)

**THOMAS
RAGNARSSON**

DICK LUNENBORG

DBI TECHNOLOGY
NETWORK
LEADERS

The technology network has made an energetic start! During the past months, more and more people have found us and expressed their wish to collaborate with others. Thus, having a place to find others seems to fulfill a need.

The network founding group organized an initial meeting in order to get to know each other, to share ideas and objectives and to explore what the network should offer. The meeting was held on March 19 with almost 40 active participants, coming from different countries and continents, and we may say it was a success. Even though we couldn't meet in person due to the Corona pandemic, people around the world joined forces in this online session. All of the participants were engaged in the work in the field of deafblindness and technology and/or lived with deafblindness themselves. Some participants had a focus on developing and testing technology, others were researchers on haptic perception and/or engineering, or were counselors of people with deafblindness who use and advise technology in daily practice. All had the knowledge to bring into the network as well as the questions to pose to other participants. Practical topics were discussed, like: How can we adapt technology for persons with congenital deafblindness? or: How can we help people with acquired deafblindness to be more independent in handling an update on their mobile phone? The societal topics were discussed as well, for example, the effect of regulations on the development of technology for persons with deafblindness. In the end, we had too little time

to really go deep into the issues, but it was a good way of getting to know each other and getting to know each other's areas of experience.

We were also very lucky to have Linda Eriksson, who has been sharing her experiences with live captioning during such meetings, being a person with deafblindness. An external organization, skrivtolkning.se, willingly provided a live captioning service for the meeting. As Linda clearly explained, the automatic captioning of the meeting-platforms is not accessible for persons with deafblindness who use Braille, yet.

At the end of the meeting, we exchanged how we would like to continue as a network. A couple of the suggested ideas for collaboration will be explored further, including a shared folder for new publications, a platform for exchanging ideas and questions and a series of meetings/ webinars in which participants can present their work. We are looking forward to continuing the inspiring work of this group of people!

And if this report makes you interested in joining our network: everybody is welcome, regardless of how much experience or knowledge you have. You may join by sending an e-mail to mworm@bartimeus.nl with Add Me to the DBI Technology Network as the title.

Updates from Ireland

The Anne Sullivan Centre in Dublin, Ireland has carried on despite the global pandemic. Our 13 residents and 2-day service users have managed to continue their day-to-day life with the support and dedication of the staff at the Centre. With reduced family visits, government restrictions, and typical daily activities cancelled, it wasn't easy. But our residents have celebrated milestone birthdays, learnt new skills, and participated in some new ASDAN educational modules. It is not the time anyone could have predicted, but we are all resilient and as a result, so are the people we support.

DEIRDRE LEECH

**HEATHER
COLSON-
OSBORNE**

ANNE SULLIVAN
FOUNDATION
DEAFBLIND
OUTREACH
SERVICES

[INFO@
ANNESULLIVAN.IE](mailto:INFO@ANNESULLIVAN.IE)

Online Training Updates

The Anne Sullivan Foundation Deafblind Outreach team made up of Heather Colson-Osborne and Deirdre Leech, began offering an online course to upskill staff at the Anne Sullivan Centre, families of our clients, and professionals in organisations around the country supporting and working directly with children and adults who are deafblind. We have 130 persons, who completed the 5-module course so far, which looks at:

- overview of deafblindness/introduction into course
- vision and hearing impairments; guiding

- deafblind awareness and accessibility
- communication strategies and techniques
- vocational, daily living skills and community participation (adults) or strategies for young children with dual sensory loss

In addition to the course, we have offered online consultations to our clients as well as webinars on Assistive Technology and Accessible Content and Literacy Adaptations.

Research Project Update

We were lucky to have a research intern from University College Dublin working with us in the end of 2020. A summary of Emma Mernagh's research paper is below.

Communication of Children with Deafblindness in Different Settings: Parent and Teacher Perspectives are focused on communication methods between children who have deafblindness, and their parents and teachers. A



The
Anne Sullivan
Centre for people who are deafblind



The Anne Sullivan Foundation
for people who are deafblind

study was created for the purpose of this research, centred around different communication techniques and methods utilised in either home or school settings. We asked teachers and parents, separately, to identify methods used in the specific setting in which they communicate with the child, and how are they commonly used. We then drew on these responses and used them for a comparative analysis. The results of our survey were extremely important for the future training programmes initiated by the Anne Sullivan Foundation. However, the research also allowed us to dive deeper into how communication is commonly used, in which contexts, and how often.

The paper begins with the explanation of deafblindness, being a disability, the history surrounding it, and the purpose of the study, which was to identify communication methods used in different settings in a child's life, in order to promote child-centred learning and consistent communication methods for the children affected, by strengthening the outreach programme at the Anne Sullivan Foundation.

We then delve into causes of deafblindness and methods of communication. We compare Ireland and the rest of the world in terms of deafblindness being a separate and distinct disability in a legislative sense. The paper also focuses on both deafblind technologies, especially technology commonly used in school and home settings, and deafblind supports.

We outline our study in the methodology, with population and sample and a data analysis. The population consisted of parents and teachers of children with deafblindness, who are in receipt of the ASF outreach services. These children attend a variety of school settings, including schools for children with sensory impairments as well as mainstream schools. All of the children attend school in Ireland. The questionnaire was sent to 25

parents initially, and after the parent's response, we sent the questionnaire to teachers of the child, whose parents replied. The questionnaire results were anonymous, and children were identified through initials and year of birth. We could then use this as an identification to compare the teacher's and parent's response.

We used this information to create data analysis and identify trends and discrepancies in communication with children with deafblindness. We found that additional methods of communication were often used in school settings, especially the use of PECS or photographs. We also wanted to focus on how available the materials needed to communicate were to the children, as it is a goal of the Foundation to ensure children have ample access to the resources that they need for communication. We also wanted to underline the importance of the use of an organized daily calendar or timetable, one that is individualised to the student and set up in the student's primary communication method. The results of our questionnaire found only 8% of parents using one of these at home. Furthermore, we analysed the use of technology and of print/ tactile books. We found many students, who did not use these regularly, and we feel this is something we can strive to improve.

Overall, the paper highlights the importance of collaboration between parents and schools in the development of communication for a child with deafblindness. It also emphasises the importance of a deafblind professional in training and services, such as the ones provided by the Anne Sullivan Foundation. The research was very influential in the development of new training offered by the Foundation and showed parent and teacher demand for such opportunities. Lastly, we stress the need for greater resource allocation and support from the government for children with deafblindness in developing their communication.

Do you Have a Story to Tell?



Deafblind International Youth Network (DbIYN)

is inviting contributions for a unique and inspiring publication

CALLING ALL

**DEAFBLIND/SENSORY IMPAIRED
YOUNG PEOPLE AGED 14-30 YEARS**

WE WANT YOU

**TO SHARE YOUR EXPERIENCES
OF THE COVID-19 PANDEMIC**

- How has the pandemic impacted on your daily life?
- Have you had to adapt your way of communicating?
- What coping strategies have you used to remain positive?
- Have you tried any new activities or new experiences?

Contributions up to 750 words

Please submit a photo if you wish this to accompany your story

Send your stories to the network coordinator Simon Allison

youth@deafblindinternational.org

Webinar book launch Spring 2021 featuring contributors to the book



**ROXANNA
SPRUYT**

DBI COMCOM,
COMMUNICATIONS
AMBASSADOR
LEAD, DEAFBLIND
ONTARIO SERVICES
CHIEF EXECUTIVE
OFFICER, ONTARIO,
CANADA

[R.SPRUYT@
DEAFBLINDONTARIO.
COM](mailto:R.SPRUYT@DEAFBLINDONTARIO.COM)



**SAMANTHA
MARREN**

DEAFBLIND
ONTARIO SERVICES,
COMMUNICATIONS
AMBASSADOR,
COMMUNICATIONS
SPECIALIST,
ONTARIO, CANADA

[S.MARREN@
DEAFBLINDONTARIO.
COM](mailto:S.MARREN@DEAFBLINDONTARIO.COM)

Raising Awareness about Deafblindness Across the Globe. One Stitch at a Time

Deafblind International's (DbI) Communication Committee, also referred to as ComCom, in collaboration with the Communication Ambassadors, and others in the field of deafblindness, are eagerly preparing for June's deafblind awareness campaign.

This year, members of the deafblind community are invited to take part in a large scale tactile art project; yarn bombing. Sometimes known as Knitfiti, yarn bombing is a form of street art where yarn that is knit, crochet or wrap adorns an object in a public space. It is thought to originate in the United States in 2005. June's awareness campaign was inspired by Australian organizations' yarn bombing for deafblind awareness.

By coming together in June (and preparing in the preceding months) in order to yarn bomb objects in as many cities and countries as possible, ComCom strives to foster connections and unite a community with individuals, service and advocacy groups in the field, DbI members and partners, and the wider global public.

Each knit or crochet square will be attached to cover a designated community space or object in

regions across the globe. This symbolizes the coming together of people in the field of deafblindness with the goal of increasing awareness and knowledge of deafblindness as a unique disability and to influence appropriate services for people who are deafblind around the world.

As of April 20, 2021, the following organizations, committees, groups, and individuals from cities and regions in Argentina, Australia, Brazil, Canada, Cyprus, El Salvador, England, France, Germany, Greece, Guatemala, India, Ireland, Italy, Japan, Mexico, the Netherlands, Norway, Switzerland, United Kingdom, USA, and Venezuela, are participating in yarn bombing projects. Don't miss this opportunity to raise awareness about deafblindness worldwide. With each yarn bombing project, we extend our reach one stitch at a time.

We invite YOU to join us in June 2021, for a movement that will

build awareness on a global scale with a strong, united voice. Grab your knitting needles, crochet hooks, colourful yarn and get crafty! Visit the [official site](#) to download and submit your Information Form, along with a Toolkit that will help to guide your yarn

bombing project. Visit Deafblind International on [Facebook](#), Instagram (@deafblindinternational), and [Twitter](#) to share and show your yarn bombing project and progress pictures; extending the digital reach of this worldwide movement.



**Deafblind
International DbI**

**Yarn Bombing
for Deafblind
Awareness**

June 2021

WHO:
We invite **YOU** to join us in a movement that will build deafblind awareness on a global scale.

WHAT:
Global yarn bombing for our 2021 awareness campaign is an exciting and creative way to engage members of the deafblind community in a tactile art project.

WHERE:
Worldwide yarn bombing installations!

WHEN:
In June 2021; depending on the region, deafblind awareness is celebrated as a month, week, or day.

WHY:
Each knit or crochet square will be attached to cover a designated community space or object across the world. This symbolizes the coming together of people in the field of deafblindness in celebration of deafblind awareness.

HOW:
Please fill out and submit the Information Form to Sam Marren at s.marren@deafblindontario.com. You will receive monthly communications and social media materials to guide you through the process.

COVID-19:
Please follow procedures and precautions to prevent the spread of COVID-19 in your country/region, and promote the health and safety of your broader community.

Make a Wave from Coast to Coast – National Deafblind Awareness Month in Canada



**SAMANTHA
MARREN**

DEAFBLIND
ONTARIO SERVICES,
COMMUNICATIONS
AMBASSADOR,
COMMUNICATIONS
SPECIALIST,
ONTARIO, CANADA

[S.MARREN@
DEAFBLINDONTARIO.
COM](mailto:S.MARREN@DEAFBLINDONTARIO.COM)

Each June, people with deafblindness, service providers, and supporters come together to Make a Wave from Coast to Coast, with a passion to make a difference and raise awareness.

This June, the National Deafblind Awareness Month (NDBAM) Committee in Canada will be Making a Wave from Coast to Coast across the country with the goal of raising awareness about deafblindness. Members of the NDBAM Committee are excited to take part in Deafblind International's (DbI) global yarn bombing movement.

The NDBAM Committee is a collaborative effort that includes organizations from British Columbia, Manitoba, New Brunswick, Nova Scotia, Ontario, and Quebec. Representatives from all provinces are engaging in yarn bombing projects in coordination with their networks.

"Yarn bombing represents a unique and creative way for communities to work together to raise awareness during National Deafblind Awareness Month, especially with increased social distancing protocols in place," says Karen Madho, Co-Chair of the NDBAM Committee and Senior Coordinator of Public Relations at DeafBlind Ontario Services.

Penny Leclair, Co-Chair of the NDBAM Committee adds, "yarn bombing is a safe way to draw public attention to our awareness efforts, especially those who do not know anything about deafblindness."

"It is my hope to motivate other people who are deafblind to get involved in bringing awareness of our needs and abilities to the public. I am always looking for ways to make others more aware of what life is like for Canadians who are deafblind," says Penny, a member of three boards of directors; the Canadian National Society of the Deaf-Blind, CNIB Deafblind Community Services, and Barrier-Free Canada - Canada Sans Barrières.

In Canada, June 2021 marks the 6th anniversary since a motion has been passed in the Senate of Canada declaring June as National Deafblind Awareness Month.

"As each knit or crochet square comes together to cover a designated community space or object, it symbolizes the coming together of people in the field of deafblindness in a tactile way. We are excited to raise awareness with yarn bombing projects across the country, along with being part of a bigger, global initiative," says Karen. To join the movement in Canada, please contact Karen Madho (k.madho@deafblindontario.com).



DEAFBLIND AWARENESS MONTH
Make a wave from coast to coast

MOIS DE LA SENSIBILISATION À LA SURDICÉCITÉ
Créez une vague d'un océan à l'autre

Symposium: Living through Touch – Smart Haptic Communication for Inclusion, Accessibility and Participation

[SUITCEYES](#) is an EU Horizon 2020 funded project (2018-2021) that is developing policy-informed haptic interfaces using smart textiles for people with deafblindness. The end goal for users is extended modes of communication and improved possibilities for meaningful, independent living.

We are excited to host the Symposium Living through Touch. Smart Haptic Communication for Inclusion, Accessibility and Participation. This event will mark the approaching to the end of our project. Our main motivations are as follows:

- to represent the latest research results both from [SUITCEYES](#) and related technology areas;
- to raise awareness and engage with high-level decision-makers towards improved policies and life opportunities for people with deafblindness; and
- to promote continued engagement and actions after the end of the project.



SUITCEYES

Date: May 17-18-19, 2021

Time: 12:00-17.00 CET

Venue: Online

Fees: Free

For more information on the schedule and registration [click here](#).

How to Become a Bridge, not a Barrier: Building Peer Relationships for a Young Man with Congenital Deafblindness using Multiparty Interactions in the Tactile Modality

Based on a Thesis for the MSc in Communication and Deafblindness



LILIAS M. LISTON

MSC

LMLISTON38@GMAIL.COM

This research explores a global problem for people with congenital deafblindness (CdB): the barriers, impeding the development of friendships. The starting point was the discovery that, at 18, Angus, my very sociable son, who has CdB, perceived to have no friends.

Friendship is one of the things that makes life worthwhile. C.S. Lewis (1960 in Lewis, 2016) wrote: "Friendship is unnecessary, like philosophy, like art...It has no survival value; rather it... gives value to survival." Close relationships are crucial for "optimal developmental environments" (Nafstad & Rødbroe, 2015, p.22) and peer interactions are vital for communicative development (Rødbroe & Janssen, 2006). The choice is essential. The research has shown that the "inability to choose social relationships is a direct cause of loneliness" (Jo Cox Commission, 2017). Lack of choice of assistants (Snow, 1991), and of those who people with CdB interact with, create barriers for the development of friendships.

The tactile modality is vital for people with CdB (Rødbroe & Janssen, 2006). However, low readability of communicative acts presents "a reciprocal challenge in all communicative relations" (Nafstad & Rødbroe, 2015, p.22) and can lead to communication being perceived as challenging behaviour. This can then result in risk assessments dictating that a person with CdB is positioned out of reach of peers. For a person with CdB this distance is a barrier to the development of communicative relationships (Gregersen, 2018).

People with CdB commonly engage in two-party interactions (Lundqvist et al., 2013). Multiparty conversations, however, are a natural feature of social relationships

and result in a fellowship between participants (Lundqvist, 2012).

Key factors in the development of social relationships were explored: availability, addressivity, participation, and agency (Linell, 2009; Lundqvist, 2012; Lundqvist et al., 2013; Nafstad & Rødbroe, 2015; Rødbroe & Janssen, 2006). Availability was subdivided into physical, social, and emotional availability with social and emotional availability of a partner a prerequisite for building communication (Nafstad & Rødbroe, 2015) and by implication, relationships (Liston, 2020). Addressivity included response and reciprocation with mutuality fundamental to the development of the persons' relationship with the world around them (Nafstad & Rødbroe, 2015).



Fig. 1. Pre-intervention: Angus sitting alone at his own table eating lunch. An empty chair on his left is for a support worker.

Changes were introduced in the physical environment, staff behaviour, and lunchtime routine.

The physical environment was changed by moving students and staff from individual tables to a shared table, that is the change from a two-party to a multiparty setting.

Staff behaviour was changed by asking for interaction between students to be actively supported in the tactile modality. Staff was to support from a less dominant position, sitting rather than standing, thus minimising any barrier between students. Changes

The setting for the research project was lunchtime in the dining room of a college for students aged from 19 to 25 with complex needs including CdB. Student participants were Angus, Leo, who has CdB, and Claire who has complex communication needs, is registered as severely visually impaired but has no known hearing impairment. There were six staff participants.

Prior to the intervention, all students were sitting separately at the individual tables. The supporting staff brought food but the interaction was minimal and primarily imperative in nature. Student participants were filmed to create a baseline.

in the lunchtime routine included supporting students to greet each other in the tactile modality and touch each other's plates to raise awareness of sharing a common activity. Students were supported to help each other by putting plates into the washing up bowl, washing them, and saying "Goodbye" in the tactile modality.

Quantitative data was collected from videos of Angus's Baseline, Days 1, 8, and 15. The qualitative data was received from focus group discussions with staff before and after the intervention, and from field notes.

Starting from the Day 1, students have shown awareness of each other's presence. The data showed a clear increase in physical and social availability of peers to Angus but less so in emotional availability.

A clear increase in students addressing each other was seen but there was very little peer response or reciprocation. The coding schedule, however, only allowed for immediate response or reciprocation. Staff reported that on Day 14 Angus was working with Claire with support. He then looked at Claire, reached for his cup, without prompt or support, and passed it to her. After he reached it over, he tapped Claire's hand. On Day 15, Angus was seen to pick up his cup and placed it in front of himself. Claire, who has very restricted movement in her arms, then moved her cup slowly across the table towards Angus. While this was happening, Angus looked up at Claire, smiled, looked down again and seemed to think about what was happening. About five minutes later Angus, unprompted and unsupported, reached across his support worker to tap Claire on the hand. The coding schedule records these as individual, unconnected acts. However, if considered as an interactional

sequence, these acts look like reciprocated interaction between two partners. It raises the question, if it had been coded differently, would more reciprocal interaction have been observed? Are we, therefore, looking at the development of a social relationship between peers in a very short time?



Fig. 2. Day 15a: Angus reaches across in front of his support worker, unprompted and unsupported, to touch Claire on the hand.

Participation with peers and peers exercising agency towards each other increased.



Fig. 3. Day 15b: Angus and Leo participating in placing Leo's plate into a washing up bowl together.

The qualitative data demonstrated changes in staff perceptions, attitudes and practice. In Focus Group 1, the staff felt that the students could not engage with each other. The issue of safety was raised, the expressed anxiety concerned the perceived risks of bringing students with challenging behaviours within reach of each other and the unpredictability of students' behaviour.

Focus Group 2 reported that Angus no longer grabs out at people. It was later reported that this continued over the eight months

until the college closed due to Covid-19. The staff also reported that anxieties about students being near each other had lessened saying, "We've seen it can work". One staff participant shared, "Before we used to stand back a lot more, but...my mindset was: It's their breaktime. Give them space...that was the attitude but actually sitting round together in a more social aspect, it's like what you do at home with your family, so it's nice. It feels more comfortable..." All staff agreed they now enjoy lunchtime more.



Fig. 4. Day 15c: Multiparty interaction.

The approach was extended across the dining room with most students now eating lunch at shared tables, in multiparty rather than two-party settings. This led to the appearance of more opportunities for the development of social relationships with peers for more students than the original case study group. The atmosphere is calmer; students choose to sit with peers from other classes and staff interacts with students as a group resulting in a "lovely and relaxed environment".

A multiparty approach in the tactile modality is now used in the classroom where Angus and Leo further developed their growing relationship.

In conclusion, the results have implications for how the optimal environment for the development of peer relationships is created, and for how people with CdB are best supported within those environments if the risks of social isolation and loneliness are to be minimised.

References

- Combatting loneliness one conversation at a time.* (2017). Jo Cox Commission on Loneliness. Retrieved from https://www.jocoxloneliness.org/pdf/a_call_to_action.pdf
- Gregersen, A. (2018). Body with body: Interacting with children with congenital deafblindness in the human niche. *Journal of Deafblindness Studies on Communication*, 4, 67-83.
- Lewis, C. S. (2016). *The four loves*. London: HarperCollins.
- Linell, P. (2009). *Rethinking language, mind, and world dialogically. interactional and contextual theories of human sense-making*. Charlotte, NC: Information Age Publishing, Inc.
- Liston, L. M. (2020). *How to become a bridge, not a barrier: Building peer relationships for a young man with congenital deafblindness using multiparty interactions in the tactile modality*. (Unpublished MSc). University of Groningen.
- Lundqvist, E. K. (2012). *Rethinking interactional practices in the tactile modality. A comparison between two-party and three-party interaction with persons with congenital deafblindness* (Master of Science).
- Lundqvist, E. K., Klefstad, L., & Seljeseth, T. (2013). *Feel my language* (L. Zachø Trans.). University Hospital of North Norway, Regional Centre for People with Deafblindness. Retrieved from www.unn.no
- Nafstad, A. V., & Rødbroe, I. B. (2015). *Communicative relations: Interventions that create communication with persons with congenital deafblindness* [Kommunikative Relationer] (K. Schou Trans.). Materialecentret, Aalborg: Statped Sørøst, Fagavdeling døvblindhet/kombinerede syns-og hørselsvansker.
- Rødbroe, I., & Janssen, M. (2006). *Communication and congenital deafblindness 1 congenital deafblindness and the core principles of intervention*. St. Michielsgestel, The Netherlands: VCDBF/Viataal.
- Snow, J. (1991). *Great questions the writings of Judith Snow*. Ontario Canada: Inclusion Press.

Connecting Youth and Adults with Acquired Deafblindness: An Action Research Study to Gain Insights into the Benefits of Age Diversity in Peer-Matching

Deafblind research in times of Corona pandemic and novel insights gained due to this inadvertent unique event. The article is an abstract summary of the Master Thesis of the Communication and Deafblindness master's programme at the University of Groningen, the Netherlands.

Intergenerational peer relationships are almost nonexistent within the deafblind population and do not naturally occur. The youth and non-family adults are physically, socially, and psychologically disconnected in today's society and especially in the context of segregated deafblind residential assisted living facilities. Despite that, the research shows that organizations, communities, and society profit at large from connected youth and adults. Furthermore, in the 20th century, one of the most noteworthy monumental demographic changes was the drastic increase in life expectancy, which resulted in greying of the world's population. More of us live longer lives and this has resulted in more years of linked lives between the young and old people. The new normal is years of interconnected "shared lives" between generations.

Against this background of ageing demographic trends and ever-increasing years of connected shared lives, the aim of my Master research was to bridge the gap between adult residents of an assisted living facility for deafblind and students of a special needs school for deafblind in Germany. The students of the school for the deafblind do not interact with adult residents on a regular basis although the two populations are resided using a shared-site model. Consequently, deafblind youth has very limited access to older deafblind adults as role models or mentors. Therefore, it was hypothesized that adults with acquired deafblindness could play an important role in the lives of students with acquired deafblindness. Hence to evaluate the feasibility of setting up such an intergeneration programme at a deafblind institute the main research question



**VIKRAM
CHOUDHARY**

THE DEUTSCHES
TAUBBLINDENWERK
GMBH, SPECIAL
NEEDS EDUCATOR
IN PROJECTS &
SERVICES

[V.CHOUDHARY@
TAUBBLINDENWERK.
DE](mailto:V.CHOUDHARY@TAUBBLINDENWERK.DE)

was as follows: What are the barriers and facilitators for frequent interaction between youth and adults with acquired deafblindness?

The study design represented a participatory action research (see Fig. 1), based on grounded theory and indoor/ outdoor activities based approach. Two pairs of youth and adults with acquired deafblindness, employing different forms of tactile communication systems and using various assisted digital communication technologies, participated in the research study (see Fig. 2). These activities were used as a vehicle to facilitate intergenerational social interaction between participants (see Fig. 3).

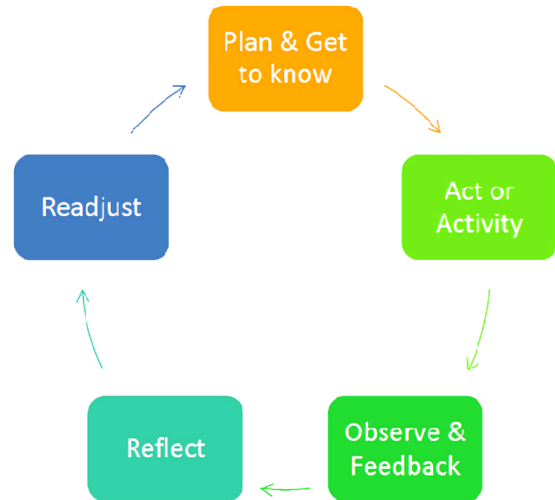


Fig. 1. Action research cycle

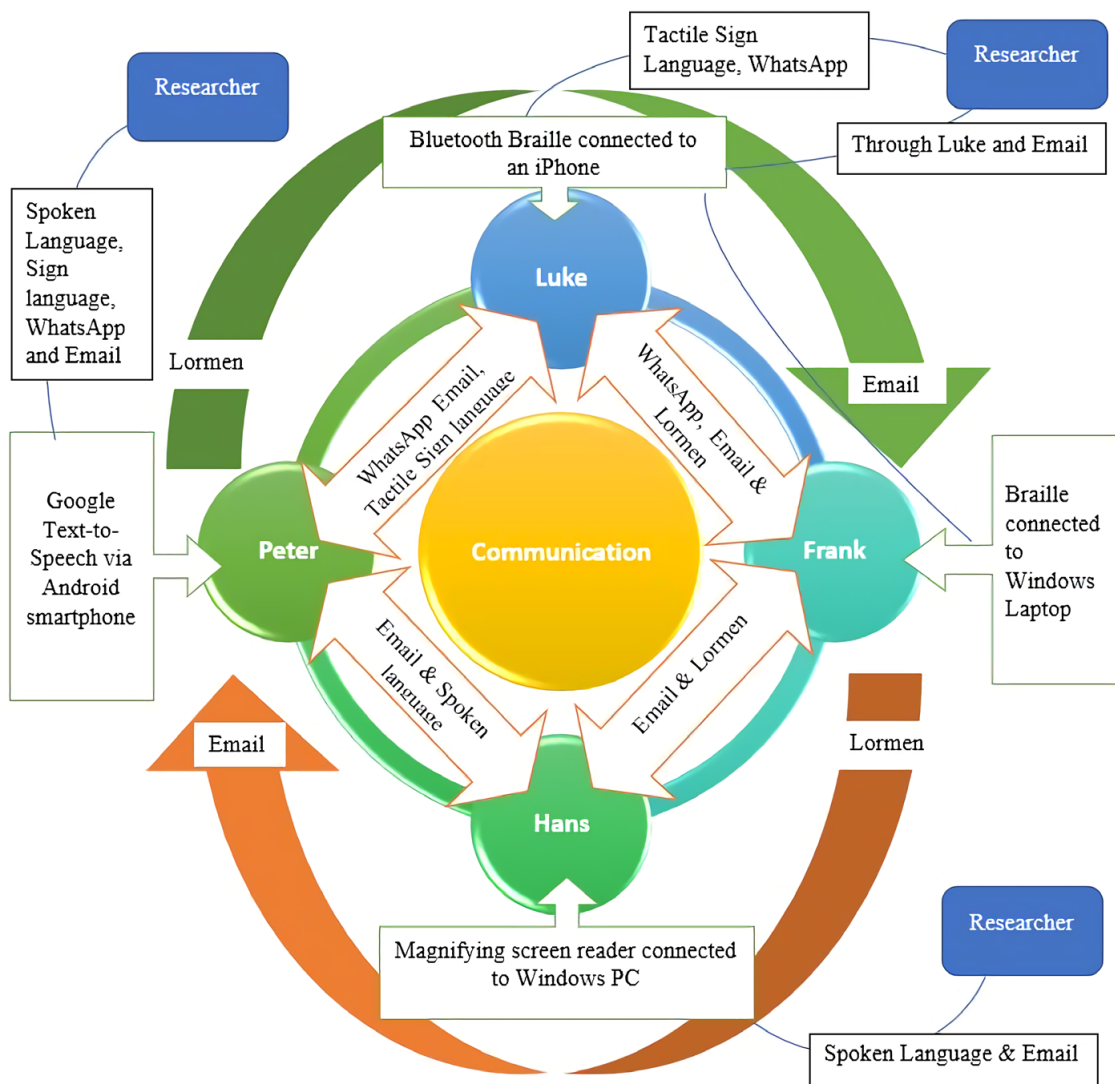


Fig. 2. Complications of communication between participants and researcher including use of participant's specific preferred assisted technologies

- 
- Cooking together
 - Baking a cake
 - Visiting a Brewery
 - Visiting a museum
 - Going for a jungle walk
 - Skiing
 - Going clubbing
 - Indoor climbing wall
 - Fitness in the park
 - Visiting a farm
 - Driving a tractor
 - Driving a car, motorcycle
 - Going inside a cave
 - Visiting a loud factory
 - Visiting Volkswagen
 - Going for a beach walk
 - Sailing or paddle boating
 - Overnight camping
 - Ice hockey and football stadium
 - Live music concert
 - Horse riding
 - Going to a restaurant
 - Going to a lake for a picnic
 - Hot air balloon ride
 - Flying together to another country
 - Speaking to a deafblind person from a different country
 - Listening to loud music with base
 - Playing cards and drinking

Fig. 3. All agreed activity ideas of four participants

However, my research was not immune to the effects of the ongoing COVID-19 pandemic and subsequent social distancing rules placed by the German government. Physical contact between the adults and youth was not allowed. The participants had to adapt their interaction and move all communication to an online-based platforms such as WhatsApp and Email. This forced the communication adaptation resulting in gaining novel insights due to this unplanned event.

This led the participants to decide for themselves to use Email and WhatsApp, to interact more efficiently, independently and keep their interaction going. The participants agreed to include the researcher into the in-group email communication in order to collect data and facilitate their interaction online. The participants started finding out who of them could use online communication tools and assisted technologies. Due to the Coronavirus social distancing, the rate of communication in the group increased dramatically and everyone started sending emails, and “organic communication” started among all participants. The content analysis of digital conversations among the participants was coded using the analysis process. The overriding themes of these emails were “solidarity, support, exchanging information and updating each other”, ever-changing rules and Coronavirus pandemic. Finally, the group decided among

themselves to exclude the researcher from the email conversation chain. The researcher contacted the youth participants and enquired about his deletion from the group email and the youth replied, “We are talking about our private things now!”

Another important novel finding of the study was connected to the current Coronavirus health crisis. The activities, planned by the four participants, could not be undertaken due to the travel and physical contact restriction. However, the activities were merely used as a vehicle to foster and facilitate group intergenerational interaction. In this regard, the discussion of Coronavirus by the participants proved to be a natural authentic group topic that they could experience together. This proved to be even better than an artificially constructed activity idea to facilitate conversations and relationship building.

Finally, the pandemic provided a unique opportunity for deafblind participants to communicate with each other away from the influences of their caregivers, support staff or any mediators. The forced use of online-based communication tools cut the middle man in the communication and resulted in direct interpersonal interaction between the deafblind youth and adults. This proved to be essential in creating an authentic social

bond. Hence, the pandemic provided the deafblind participants with much-needed and often-overlooked “space” and “privacy” to create their own opinions, group identity and foster a deafblind cultural identity away from the outsiders’ influences.

In regards to the main research question, the study found that communication complications, dependency on caregivers, mobility issues, willingness to participate were found to be among the significant barriers, whereas institutional support, caregiver involvement, financial support, personal motivations, the authenticity of the interaction, along the intrinsic human desire to socialize were considered as major facilitators in implementing an intergenerational exchange program between deafblind residents at an assisted living facility. Besides, the research also showed that frequent dyadic peer interaction also benefited deafblind adults by providing purpose, community, and empowerment.

Another significant finding of the present study was the importance of institutional support as one of the prerequisites for the

connection of two sub-groups of the deafblind population. Therefore, a better understanding of intergenerational social interaction can contribute to better planning of deafblind services in a shared-site model. For example, living arrangements at a deafblind assisted living facility could include mixed-aged intergenerational housing. Also, from a pedagogical perspective, the adult deafblind individuals could form a part of a teaching team and provide assistance in educating the young deafblind pupils by providing their unique knowledge and perspective.

In conclusion, reducing intergenerational social isolation within the deafblind community may improve the quality of life for deafblind individuals by supporting self-determination, self-advocacy, self-empowerment, self-assistance, and providing peer support between older and younger deafblind individuals. Hence, two interconnected generations may benefit from each other. The resulting social bonds can lead to lifelong friendships, memories, opportunities to reminisce and lead to the development of a “deafblind culture”.

A European Online Dictionary for Social Haptic Communication

Social haptic communication enables deafblind people to receive relevant auditory or visual information through touch. The Social Haptic Signs for Deaf and Blind in Education is an Erasmus+ project on social haptic communication. The project's aim is to collect haptics used in four countries into an online dictionary. This article provides information about the state of the art regarding social haptic communication and about the project in its initial and future stages.

Social Haptic Communication

Following Lathinen (2008), we use the term “haptics” to refer to the single signs/messages on the body, and “social haptic communication” (SHC) to refer to the communication system which makes use of haptics. The parts of the body involved in social haptic communication are usually the back, the upper arm, the hand, the leg/knee, and the foot (Bjørge & Rehder 2015). As Lahtinen (2008) points out, the whole human body can actually turn into a holistic system able to receive and interpret touch-related messages.

Social haptic communication can help people with deafblindness to understand better what is happening around them. It can convey such information as the environmental description, emotional feedback, warnings, and others.

SHC is also useful when the hands of a deafblind person are busy exploring something or communicating to someone else e.g. by using tactile sign languages; when a deafblind person wants to receive information discreetly; and when the environment is too noisy for the hearing aids or cochlear implant to work properly (Hesse & Nielsen 2018). Multi-impaired deafblind can also benefit from SHC since they often need to receive information through multi-sensory channels. This can be achieved by combining SHC with audio or visual inputs. For those who rely on touch as the main source of information and can only process very basic intuitive messages, SHC can actually become fundamental for communicating with the world around them.



LAURA VOLPATO

CA' FOSCARI
UNIVERSITY OF
VENICE

LAURA.VOLPATO@UNIVE.IT



**PATRIZIA
CECCARANI**

FONDAZIONE LEGA
DEL FILO D'ORO

CECCARANI.P@LEGADELFILODORO.IT



**ANNA
CARDINALETTI**

CA' FOSCARI
UNIVERSITY OF
VENICE

CARDIN@UNIVE.IT

SHC should not be intended as a substitution of other communication systems, such as, for instance, tactile sign language.

State of the Art

Despite touch signals having probably been used for much longer time, the earliest research about SHC started in the nineties. Riitta Lahtinen and Russ Palmer gave a huge contribution to the development of SHC in different countries (Lahtinen 1999, 2003, 2008; Lahtinen & Palmer 1996, 1997, 2000, 2005; Palmer & Lahtinen 1994, 2005, 2013; Lahtinen et al. 2010, 2012, 2016, 2018)¹. Riitta Lahtinen is a Finnish hearing and sighted researcher and interpreter who investigated the process of creation and adaptation of haptics thanks to the cooperation with Russ Palmer, a deafblind musician and her husband. They talk about a “grammar of touch”, which regulates the combination of minimal touch variables, which they call “haptemes”, into more complex and complete messages, which they call “haptics” (Lahtinen 2008).

Haptics are known and used in other countries as well. For instance, Trine Naess, a young Norwegian deafblind woman, contributed to the collection and standardization of haptics in Norway. In 2010, another Norwegian deafblind woman, Berit Øie, introduced SHC to the Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC) in New York, setting the basis for a further cooperation of U.S. and Norway which resulted in a book about SHC (Björge & Rehder 2015). In Denmark, the National Association

The Project

[The Social Haptic Signs for Deaf and Blind in Education](#) is an Erasmus+ project on social haptic communication. The aim of the project is to collect haptics used in four countries (Estonia, Italy, Portugal, and Sweden) and make them available online for anyone interested in learning them. Each haptic will be video-recorded, portrayed in pictures, and described in simple words. The project especially focuses on the needs of

Rather, it is an additional source of information, able to fully exploit one’s communicative skills.

of Deafblind people has been working on collecting, standardizing, and sharing their SHC variant (see Hesse & Nielsen 2018). The Swedish Nationellt kunskapscenter för dövblindfrågor (National Knowledge Center for Deafblind Issues) presents a collection of the most important haptics used in Sweden on [their website](#). In the Netherlands, a recent [country-wide project](#) started collecting, developing and standardizing haptics as well. SHC is now used in many countries, but information about it is not always easy to retrieve or share.

Studies on touch do not specifically explore SHC, but could provide useful information for a deeper understanding of it. For instance, we know that we are aware of 1-5 visual stimuli at one time, but our tactile awareness is limited to 1-3 stimuli (Gallace & Spence 2014). This could imply that SHC can be performed simultaneously with other tactile communications as long as it does not exceed a certain limit of tactile stimuli per time. We also know that intense practice in using parts of the body to receive tactile information can lead to big improvements for those parts of the body, as measured in terms of tactile discrimination thresholds (Gallace & Spence 2014). This could imply that training in receiving multiple tactile stimuli, such as SHC and other tactile information, can improve our discrimination skills.

deafblind individuals in educational settings. The project leader is Thomas Lydell-Olsen from the [European Sign Language Centre](#) based in Sweden. Each country can count on the cooperation of the deafblind community for the collection of the haptics. The Italian team is coordinated by Ca’ Foscari University of Venice which collaborates with the association [Lega del Filo d’Oro ONLUS](#). Riitta Lahtinen and Russ Palmer give their

¹ For further references, see Russ Palmer and Riitta Lahtinen’s webpage at www.russpalmer.com.

contribution to the project by sharing their knowledge about SHC with the researchers in group sessions and individual sessions. The project started in September 2019 and will end in August 2022. By then, the partnership will have collected and documented haptics. The result will be an open source online haptic dictionary.

The COVID-19 pandemic has made our work more difficult given the “haptic nature” of the project and it forced us to repeatedly adjust our research plan. Our first step considered gaining knowledge about SHC through studying literature and through

online training sessions with Riitta Lahtinen and Russ Palmer. We also collected information about experiences of SHC in other countries through emails and online meetings. Secondly, we focused on the web platform for the SHC dictionary and discussed the accessibility features that it will need for both the deafblind users and their contact persons to be able to access it. Some experts on assistive technologies for people with deafblindness gave their contribution to our discussion. Thirdly, we started teaching SHC fundamentals to members of the deafblind community.

Future Development and Conclusions

Our future steps will include the following: (online) training for deafblind individuals and their contact persons on SHC; gathering feedback and new haptics; re-discussing the new haptics with the whole group of trainees (who will become trainers themselves). We will also further monitor the accessibility features of the online platform and discuss them with deafblind users. Together with our deafblind trainers we will spread knowledge about SHC amongst the deafblind community and the community of family members, caregivers, interpreters.

The Erasmus+ project Social Haptic Signs for Deaf and Blind in Education will result in an online open access dictionary for social haptic communication, which is, hopefully, only a starting point for a much larger cooperation.

We think that the project can have a great impact on the deafblind communities by improving the quality of the services they have access to and therefore empowering them. We also believe that all those living and/or working with deafblind and multi-impaired deafblind people can find in SHC a great support in their daily activities.

References

- Bjørge, H. K., & Rehder, K. G. (2015). *Haptic communication: The American edition of the original title haptisk kommunikasjon* [Kindle DX Version]. Retrieved from Amazon.com
- Gallace, A., & Spence, C. (2014). *In touch with the future: The sense of touch from cognitive neuroscience to virtual reality*. OUP Oxford. 104-105.
- Hesse, P., & Neilsen, G. (Ed.) (2018). *Haptic signals - 139 new and known signals*. The Danish Association of the Deafblind. Retrieved December 15, 2020, from Fddb.dk website: <https://www.fddb.dk/media/141088/haptic-signals-139-new-and-known-signals-english.pdf>
- Lahtinen, R. (1999). Holistic and interactive communication methods. In Peckford, B. & Hawcroft, L. (Ed.) *Proceedings of an international symposium in interpreting for deafblind people*. Prontaprint, Durham, UK, 64-65.
- Lahtinen, R. (2003). *Development of the holistic social-haptic confirmation system. A case study of the yes & no - feedback signals and how they become more commonly and frequently used in a family with an acquired deafblind person*. Licentiate Thesis, Department of Teacher Education, University of Helsinki.

Lahtinen, R. (2008). *Haptics and haptemes: a case study of developmental process in social-haptic communication of acquired deafblind people: doctoral dissertation*. 1st ed. Frinton-on-Sea, 196 p. 2008. Publisher: A1 Management UK.

Lahtinen, R., & Palmer, R. (1996). Holistic family communication, spoken language by touch is more than just words. *The 4th European Deafblind Conference, Finland (Espoo)*, June 1996.

Lahtinen, R., & Palmer, R. (1997). Theoretical basis of holistic communication for dual-sensory impaired people & family members. *EUSSG & 4 th IAEDB (DbI) European Conference Proceedings*, Madrid, Spain.

Lahtinen, R., & Palmer, R. (2000). *Holistic & interactive communication methods with acquired deafblind people & families - a practical approach. Joint training initiative, distance learning course* (incl. video). Manchester University, UK.

Lahtinen, R., & Palmer, R. (2005). *The body story: creating musical images through touch* (CMIT). City-Offset, Tampere, Finland.

Lahtinen, R., Groth, C., Palmer, R. (2018). Sound descriptions of haptic experiences of art work by deafblind cochlear implant users. *Multimodal technologies and interaction*, 2(2), 24.

Lahtinen, R., Lahtinen, M., Palmer, R. (2010). *Environmental description for visually and dual sensory impaired people*. Art-Print, Helsinki, Finland.

Lahtinen, R., Palmer, R. & Ojala, S. (2012). Visual art experiences through touch using haptics. *Procedia - Social and Behavioral Sciences* 45, 268-276. Retrieved from <http://www.sciencedirect.com/science/journal/18770428/45>

Lahtinen, R., Palmer, R. & Tuomaala, S. (2016). Using haptics in health care settings. *DbI Review* 56, 18-19.

Palmer, R., & Lahtinen, R. (1994). Communication with Usher people. *Deafblind Education*, July – December, 1994, p. 7-9.

Palmer, R., & Lahtinen, R. (2005). Social-haptic communication for acquired deafblind people and family: Incorporating touch and environmental information through holistic communication. *DbI Review* January – June 2005, p. 6-8.

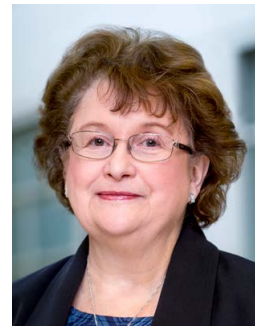
Palmer, R., & Lahtinen, R. (2013). History of social-haptic communication. *DbI Review* 50, 68-71.

The Applicability of the HELP and BCP Assessment Instruments to Students who are Deafblind

Introduction

This is the fourth in a series of articles about the assessment of children and/or adults who are deafblind. This article will begin with some guiding principles about the selection of commercially produced formal assessment instruments to be used with learners who are deafblind. We will then present two formal assessment instruments, Hawaii Early Learning Profile, 0-3 years (Warshaw, 2006) and 3-6 years (Teaford, Wheat, & Baker, 2010) and Behavioral

Characteristics Progression (BCP; Vort Corporation). Each instrument will be described, including the areas assessed and scoring. A description of how each instrument addresses the area of communication is included. It should be recognized that formal assessment instruments will need to be paired with structured informal assessments to best capture the full range of the learner's knowledge and skills.



SUSAN M. BRUCE

SUSAN.BRUCE@BC.EDU

Considerations when Selecting Formal Assessment Instruments

Venn (2014) provides five guidelines to consider the choice of assessment instruments for use with learners who have severe and multiple disabilities. These guidelines are equally important when selecting assessment instruments to use with learners who are deafblind. The first, is called “adaptable response modes” (p. 158), meaning that there is a flexible point of view about how the learner will demonstrate knowledge, such as expressing knowledge in different communication forms/modes or showing us what they know in a way that is different from

the one suggested in the assessment item. The second guideline is called “flexible administration” (p. 158), meaning that data about the learner's performance can be collected in different ways, for example through observation (which may include previous observations based on daily interactions with a learner) or interview, as opposed to the need of direct testing. The third one concerns that the tool has “provisions for partial credit” (p. 158). This concerns giving credit to a learner for either partial performance of the skill or performance of the skill with



STEPHANIE BIANCO

BOSTON COLLEGE

prompts. The fourth is a “wide sample of behavior or skills” (p. 158). When there is a large number of items that measure performance on a wide range of behaviors or skills, it is more preferable to use the assessment instrument which would be sensitive to small increments of student development or progress. Such instruments are often a better guide for selecting appropriate points of instruction. The fifth guideline is that the assessment instrument “provides procedures for developing an intervention plan” (p. 158). Some instruments, including the HELP and BCP, provide curricular guidance that allow the team to seamlessly connect assessment results to decisions about what to teach. Curricular guides are especially helpful for early career teachers, when a teacher has many new students, or the class size or caseload is relatively large.

The professionals must also consider the theoretical grounding of an assessment instrument. A tool grounded in developmental theory will often capture skills in roughly the same sequence that they would be achieved by children without disabilities. We

Hawaii Early Learning Profile (HELP)

The Hawaii Early Learning Profile (HELP) is a developmental assessment, meaning that the items are sequenced developmentally as they would be achieved by children without disabilities. The HELP has a 0-3 years version (Warshaw, 2006) and a 3-6 years version (Teaford, Wheat, & Baker, 2010). The HELP is also a curriculum-based assessment instrument because it comes with an activity guide that can be used to develop lessons. So, the assessment team can identify an evaluation item that a child hasn’t achieved yet or that represents an emerging skill, then turn to the corresponding item number in the Activity Guide to glean ideas about what to teach. The HELP 0-3 includes an additional guide to support professionals providing services to young children in the family home.

Both HELP 0-3 and 3-6 versions address the following major areas of development:

should not assume that the developmental sequence would be the same for a child who is deafblind. The developmental tools should not be used alone with youth beyond 12 years old. This is because some of the early developmental skills become less important for older children to learn. Older children and youth should be assessed with instruments that consider valued adult outcomes and functional skills. Additionally, the person-centered planning approaches are valued for assessing and planning instruction for learners who are deafblind.

The educational teams serving children and youth who are deafblind may also be interested in specific assessment content, such as the assessment of tactile perception, sign language, fingerspelling, Braille comprehension, orientation and mobility, and sensory sensitivities and preferences. Perhaps, the most important thing is that the team will want to select assessment instruments that feature items that do not assume typical vision and hearing and that allow a learner to demonstrate his/her achievement across communication modes/forms.

cognitive, language, gross motor, fine motor, social-emotional, and self-help (including feeding/eating and sleep patterns). The HELP 0-3 includes items on pivotal milestones such as means-end, object use, symbolic play, and development of a sense of self. The second step, the HELP 3-6, includes items on grouping and categorization, sequencing, and expanding utterances in speech or sign language.

Scoring for both HELP versions include whether the skill is present or not, and also the measurement of emerging or prompted skills, which is important for this population of learners. An assessor can also decide that an item is inappropriate (which may be due to deafblindness). The scoring also recognizes atypical performance of a skill (such as excessive demonstration of a specific skill).

Communication

One of seven core areas assessed in the HELP is language, which encompasses various aspects of communication in early childhood. Within the area of language there are categories, which include understanding of the words meaning, understanding and following directions, expressive vocabulary, communicating with others, learning grammar and sentence structures, development of sounds and intelligibility, and communicating through rhythm. These sections include

both verbal and nonverbal behaviors. The HELP guides the assessor by including the developmental level expected for each item as well as examples for variations in responses or demonstrations of the target behaviors. An assessor is given freedom to accept a variety of responses in a learner's preferred forms/modes of communication, which is critical for assessment of the individuals who are deafblind.

Behavioral Characteristics Progression

The Behavioral Characteristics Progression (BCP; Vort Corporation) is a curriculum based, developmental assessment instrument. It assesses 56 strands of development that are organized within these seven broad areas: cognition, gross motor, fine motor, social, self-help, vocational area, and language. The BCP includes some unique strands of assessment that may be relevant to individual learners who are deafblind, including: listening, sign language, finger spelling, orientation, mobility, wheelchair use, sensory

perception (by touch, smell and taste), visual motor skills, swimming, and outdoor skills.

The BCP includes a list of identifying behaviors. This list is used to determine which strands or areas should be addressed when assessing a learner. Scoring the BCP is the same as scoring the HELP, making it easier for school team members to shift from one instrument to another. The BCP also includes an activities book to support seamless transition from assessment to instruction.

Communication on the BCP

The BCP includes a variety of unique strands that could be of special interest to assessing the communication skills of individuals who are deafblind. This versatile assessment instrument can be used to assess individuals of all developmental ages and addresses basic communication to sophisticated use of language. The strands within the language area include sign language, fingerspelling, articulation, and speech reading. The assessor can use specific identifying behaviors to pinpoint what learner's communication needs may be, then use the BCP items to identify the learner's current level, and then teach

the associated skill. Each item directly corresponds to an activity in the Instructional Activities Booklet, which provides educators with step-by-step instructions for an activity to foster the skill, including the required abilities and interest level. This facet of the BCP is especially important when working with individuals who are deafblind, as teachers will be able to take into consideration the sensorimotor abilities required for the activities as well as the recommended developmental level when choosing which activities to implement.

Conclusion

Caution must be exercised when selecting formal assessment instruments for use with learners who are deafblind. Many instruments feature items that are biased toward learners with typical vision and hearing. The

teams must evaluate the appropriateness of each instrument for a specific learner. It is likely that the team will need to pair the use of formal instruments with structured informal approaches, such as the van Dijk

ARTICLES

approach to assessment, instructor-made assessments (including task analyses), and person-centered planning approaches. The primary purpose of assessment is to develop

an accurate picture of what the learner can do. This will serve as a strong foundation for elaboration of instructions for an emerging or new knowledge and skills.

References

Vort Corporation. *Behavioral Characteristics Progression*. Palo Alto, CA: Vort Corporation.

Teaford, P., Wheat, J., & Baker, T. (2010). *Hawaii Early Learning Profile, 3-6*. (2nd ed.). Palo Alto, CA: Vort Corporation (www.vort.com)

Warshaw, S. P. (2006). *Hawaii Early Learning Profile, 0-3*. Palo Alto, CA: Vort Corporation. (www.vort.com)

Venn, J. (2014). *Assessing students with special needs*. (5th ed.). Upper Saddle River, NJ: Pearson Education Inc.

The Experience of Life with Acquired Deafblindness and CI

Results from an Empirical Research-Based Inquiry about CI and Deafblindness in Denmark

Acknowledgments

The authors would like to send our thanks to the persons who agreed to be interviewed and gave us an opportunity to gain a better understanding of how a CI is experienced by someone living with deafblindness. We also thank our colleagues in CFD's deafblind counselling service for their help.

Cochlear Implant (CI) has become a common treatment for persons with acquired deafblindness in cases where the hearing loss is difficult to remediate with a hearing aid (Møller, 2003). The growing use

of CI begs a discussion about how CI affects the experience of deafblindness. It is a question that is becoming increasingly urgent as more and more people are asking, whether CI treatment is so effective in reducing the impact of the combined vision and hearing loss that a person should no longer be considered deafblind. As our study (Hansen & Uldall, 2020), based on interviews with people living with acquired deafblindness and CI, shows – the answers to these questions are complicated and have more dimensions than expected.

Existing Research

Much of the existing research literature is focused primarily on CI, being an audiological treatment option for persons with severe hearing loss. The interest has similarly been limited to the hearing outcome. The research suggests that persons with acquired deafblindness benefit from CI as much as other groups who receive the treatment. This is often typical for older research, such as Hinderink et al. (2001) report on the results from cochlear implant patients with Usher's syndrome or Wiley et al (2005), which does look at the perceived qualitative benefit of CI in children with several handicaps, but only looks at the benefits in regards to their hearing and

communication. The same focus is also observed in later studies – as e.g. Takanos et al. (2016) report on the outcomes for visually impaired patients with CI. Their study shows no significant differences in the ability to hold a conversation with others for patients with and without a visual impairment. But it contains no reflection on how CI affects the experience of acquired deafblindness. Our finding showed that the research poorly demonstrates an awareness of the interplay between vision and hearing, failing to provide insights into how persons with acquired deafblindness find that CI affects their everyday life and their perception of their deafblindness.



NIELS-HENRIK MØLLER HANSEN

PHD,
RESEARCHER AND
DEVELOPMENT
CONSULTANT

NHH@CFD.DK



TRINE SKOV ULDALL

CFD RAADGIVNING
(CFD
COUNSELLING),
SPECIALIST
COORDINATOR,
DENMARK

TUL@CFD.DK

Our Study

In our study we wanted to examine how a CI could change a person's perception of his/her deafblindness. Our study included six persons with CI and acquired deafblindness. They were selected to represent a broad range of experiences with regard to CI, life situation, age and geography. We also interviewed three advisors for persons with

deafblindness who provide special counselling to persons with acquired deafblindness and CI. All 9 participants were interviewed by one or two researchers using a semi-structured interviews guide (Galetta 2013). The interviews were transcribed in full and analysed in themes as they emerged from the text.

Results

Among the themes raised in our interviews there were the following ones:

- the informants' considerations, hopes and expectations in connection with the choice of having a CI
- the informants' experience of the time following the procedure and getting used to the new sound a CI provides
- how the change in hearing has affected perception of their deafblindness

Should I Opt for a CI?

Choosing to get a CI is a big decision for a person who also has vision loss. The study showed that this decision involves a wide range of considerations and often implied a lengthy process.

The decision whether to have a CI or not doesn't concern only hearing. The considerations about vision and the progression of vision loss often play a role too, and constitute an important part of the process. For some informants, the fear of a bad outcome of the operation played a big role. Others viewed CI

as a way to secure as much hearing as possible, given the expected progression of vision loss. These reflections may be influenced by an individual's life adjustment process¹.

Although all informants received professional advice and information prior to the surgical procedure and have been receiving them throughout the process, realistic expectations versus hope or fear may have a considerable impact on the CI decision and can also affect the experience of the follow-up and rehabilitation process.

Switching on the Sound

The experience of the period just after the operation and of having the sound switched on is experienced very differently by the informants. Having to relearn hearing is a demanding task, as a person has to get used to the new sound and undergoes a lengthy rehabilitation process. Some people experience quick progress in training, while others must struggle with headaches and fatigue.

The study identified another important factor: the challenge of not being able to use the eye sight to verify sounds. As a result, some informants feel their deafblindness differently and more severely than before the CI procedure. This is a paradoxical and

perhaps an illogical outcome, but it underscores the importance of considering a CI in relation to the person's deafblindness, not just to their hearing loss.

The advisors for persons with deafblindness point to the need for ongoing counselling to make sure the person has realistic expectations. It is important to explain that the interplay of vision and hearing might change and be aware that it may be necessary to learn new strategies to prevent fatigue even if one's hearing improves.

How Does CI Affect the Deafblindness Experience?

¹ The life adjustment process is described by Gullacksen et al., 2011

When the informants describe their experiences with a CI, they are generally pleased with the outcome. They report that their functional hearing has improved, particularly when it comes to communication in quiet settings, one-to-one conversations and alarms/signal sounds at home. The study points out that persons who have a CI and acquired deafblindness mostly benefit from CI in those situations where they did best prior to getting the implant. Thus social interactions with few people present, no background noises and a well-lit environment are still most accessible with CI as they were with hearing aids. In such situations, CI is a big improvement and makes these situations less demanding.

The informants continue to experience challenges in communication with more than one person, conversations in noisy settings, acquiring information and travelling. Challenges in these situations are particularly experienced when a person's vision does not provide sufficient compensation. That drains the person's energy and can be exhausting. In these situations, the impact of deafblindness becomes extra visible.

Our Findings

Firstly, the study suggests that CI is an important tool to improve life for persons with acquired deafblindness. Secondly, although it does improve their hearing, the new hearing is mostly helpful in certain specific situations, which the precipitants will need to adjust to and maybe develop new (hearing) strategies. Thirdly, it is important to bear in mind that deafblindness will continue to be a factor in

“Yes, I get lots of sounds. The problem is, I can't separate them out. For example, if I am at a dinner party, and I need to concentrate to hear what the person next to me is saying, that takes a lot of energy.” (Susanne, CI for 10 years on one ear and 4 years on another one).

Based on the Nordic definition of deafblindness (Nordic Welfare Centre, 2018), persons with a CI and acquired deafblindness should still be considered as belonging to the group of persons with deafblindness. Some informants find that their deafblindness even takes on a new and more prominent role in their everyday life, and that they need to re-learn to live with it in a new way, with the pros and cons of having a CI.

“It's just that the balance of my disability has tipped, I think. It's hard to get used to. Whether I'm still deafblind? To me, it feels almost as if I'm more deafblind now, but my hearing is good – better. I even heard the nightingale. I have heard more birdsongs this year than ever before.” (Heather, one CI for 11 months).

the person's everyday life, regardless how much they benefit from the CI. The new and greater amount of sounds brings new challenges in everyday life, and to many people, the progression of vision loss continues to be a fact they need to deal with continuously. For these reasons, advisors for persons with deafblindness will need to continue to focus on the life adjustment process.

References

- Hansen, N.H. M., & Uldall, T. S. (2020). *CI og døvblindhed: En undersøgelse af borgere med erhvervet døvblindheds udbytte af CI* [CI and deafblindness: A study of the benefits of CI for persons with acquired deafblindness], CFD Rådgivning.
- Henricson, C., Wass, M., Lidesam, B., Möller, C., & Lyxell, B. (2012). Cognitive skills in children with Usher syndrome type 1 and cochlear implants. *International Journal of Pediatric Otorhinolaryngology*, 76, 1449–1457.
- Hinderink, J. B., Brokx, J. P. L., Mens, L. H. M., & van den Broek, P. (2001). Results From Four Cochlear Implant Patients with Usher's Syndrome. *Cochlear Implants in Adults*, (ed.)

Hinderink, J. B.. Retrieved from https://repository.ubn.ru.nl/bitstream/handle/2066/146741/mmubn000001_349193908.pdf

Galetta, A. (2013). *Mastering the semi-structured interview and beyond. From research design to analysis and publication*. New York: New York University Press.

Gullacksen, A.C., Göransson, L., Rönnblom, G. H., Koppen, A., & Jørgensen, A. R. (2011). *Livsomsstilling ved kombineret syns- og hørenedsættelse/døvblindhed – et indre arbejde over tid*. Nordens Velfærdscenter.

Möller, C. (December 01, 2003). Deafblindness: living with sensory deprivation. *The Lancet*, 362 (special issue), 546-547.

Pietola, L., Aarnisalo, A., Abdel-Rahman, A., Vastinsalo, H., Isosomppi, J., Löppönen, H., Kentale, E., Johansson, R., Valtonen, H., Vasama, J., Sankile, E., & Jero, J. (January 2012). Speech recognition and communication: Outcomes with cochlear implantation in Usher syndrome type 3. *Otology & Neurotology*, 33(1), 38-41.

Takanos, K., Kaizaki, A., Saikawa, E. Konno, A., Ogasawara, N., & Himi, T. (2016). Outcomes of visually impaired patients who received cochlear implantations. *Auris Nasus Larynx*, 43, 242–246.

Wiley, S., Jahnke, M., Meinzen-Derr, J., & Choo, D. (2005). Perceived qualitative benefits of cochlear implants in children with multi-handicaps. *International Journal of Pediatric Otorhinolaryngology*, 69, 791–798.

At Work with Dual Sensory Loss

Introduction and Objective

This study explores experiences of people with acquired dual sensory loss (PADSL) about their participation in work life, focusing on potential success factors involved in keeping a job.

The UN Convention on the Rights of Persons with Disabilities proclaims the right of people with disabilities to equal access to all parts of society including the right to work, free choice of employment, just and favorable conditions of work, and protection against unemployment (art. 27, 2020).

Deafblindness, or dual hearing and visual sensory loss, is a unique condition. Typically, there is a poor understanding of this specific disability in society [1]. It is not easy for PADSL to be seen or heard, to make their own choices, or participate in different aspects of life that are taken for granted by others.

Having a job is important for both mental and physical health [1, 2] and is a core right for most adults in Norway. The relationship between employee and workplace

Method and Implementation

The basis of new knowledge in this qualitative study is participants' lived experiences of the phenomenon – the ability to keep a job with dual sensory loss. A phenomenological approach is thus adopted.

contains physical, social, and organizational dimensions and in the case of PADSL, both employee and employer are required to be creative in finding strategies to compensate for the combined sensory loss.

Few studies explore work experiences of PADSL, hence further research is needed. Many PADSL have a job before sensory loss becomes a challenge. The issue is how to keep a job after sensory changes in adulthood. Many have a hearing loss from an early age and learn to live with it, before vision begins to create problems later in life. This development comes late enough for most to first get an education, establish a family, develop skills, get a job, and create relationships at work.

This study aims to capture experiences of participation in work life and focuses on potential success factors contributing to keeping jobs. It develops a deeper understanding of the challenges of retaining a job for those with acquired deafblindness.

A life-world phenomenological approach provides instructive analytical tools. People who have a long-term/progressive disability are not only physically affected, but as the body changes, so does their life situation and relationship with the outside world. All



ANN-BRITT JOHANSSON

PHD, EIKHOLT NATIONAL CENTER ON COMBINED VISION AND HEARING IMPAIRMENT/DEAFBLINDNESS, SENIOR RESEARCHER, DRAMMEN, NORWAY

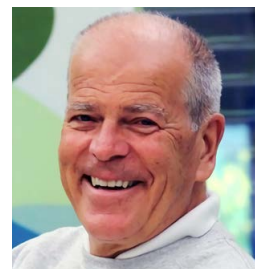
ANN-BRITT.JOHANSSON@EIKHOLT.NO



NASRINE OLSON

PHD, THE SWEDISH SCHOOL OF LIBRARY AND INFORMATION SCIENCE, UNIVERSITY OF BORÅS, SENIOR LECTURER, SWEDEN

NASRINE.OLSON@HB.SE



ROLF LUND

EDD, CLVT, EIKHOLT, NATIONAL CENTER ON COMBINED VISION AND HEARING IMPAIRMENT/DEAFBLINDNESS, SENIOR RESEARCHER, DRAMMEN, NORWAY

ROLF.LUND@EIKHOLT.NO

experiences and activities are based in the body, the lived body. In a life-world interview, one seeks to understand the themes of the lived everyday world from the participants' own perspective. This study focuses on a part of the participants' lifeworld, working life, but the working life also affects life outside work. Hermeneutics is an investigative method where, by interpreting people's actions, experiences and intentions, one can

Results

The lifeworld is the world in which we live our daily lives and is taken for granted. A regional world is a defined world, and here the workplace is. The study

Workplace

The relationship with coworkers (colleagues, immediate boss, employer) is important for a good work situation, hence PADS� typically informs the coworkers about their sensory deterioration at an early stage. This can lead to changes or reduction of work tasks or hours, or use of new tools.

According to a participant, "the knowledge is power", and it is needed to understand one's own situation or to establish an understanding among coworkers. The ability to be open does not come by itself and requires courage and a sense of security. It requires practice and enough knowledge to feel safe. It is important that everyone at work is kept informed but it's often necessary to communicate the information to coworkers multiple times, particularly in large workplaces. This can be rather tiring; thus, it is valuable to have the help of a good colleague who is willing to offer support.

In Norway, there are various governmental supports for people with disabilities, however, awareness is typically rather poor, and persons with disabilities find access to these services quite demanding.

clarify, describe and explain the life situation of others [3].

Ten PADS� participated in the study. There was a broad variation in age (30-60), location, job type, and degree of impairment. Living situations varied from being single and alone to having a family with young or adult children. These deep interviews took 1-1.5 hours each and were conducted at participants' homes (3) or workplaces (7).

identified four other regional worlds important for continuing work – home conditions, activities, social contacts, and surroundings.

Even so, all ten participants had a good knowledge of the governmental systems and all of them, except one person, had established good contacts with the local services. They all had to coordinate the efforts themselves, which required much time and energy. All ten participants used interpreters and guide services. Two of them have been using an interpreter throughout the whole working day.

The financial support for salaries is also available for employers, especially towards new employment. This was only utilized in the cases of two participants.

Organizing the work in terms of work-time, tasks, and preparation for meetings is also important. It is crucial to receive information well in advance of an activity to facilitate managing the required preparations. Booking an interpreter or transforming text to Braille may not be possible with short notice.

All participants viewed assistive technologies as important facilitators. They emphasized that the assessment of needs and testing of solutions are crucial and should be conducted by people with good competence in both technology and dual sensory loss.

Home Situation

The situation at home as a safe and supportive environment is a great work enabler. All participants expressed that at the end of a work day they felt drained and in need of

Physical Activities

All ten participants identified physical activities as important ones for their well-being and ability to work. They all

Social Contacts

The previous studies have shown that if energy levels are low after work, one prioritizes family and reduces other social contacts [1]. This was also the case for the participants who wished for more time

The Lived Body

People with a long-term or progressive condition are not only affected physically, but their relationship with the outside world is changed as well. The study started from the lived body's changed relationships with the world and was focused on work. The existential body, the perceptual body, the activity body and the social body are described as the building blocks of the living body [3]. The lived body is an intertwinement of the various bodies and cannot be seen in isolation – it must be seen as a whole.

The existential body expresses how the participants experience the way in which society sees people with disabilities in general and at work. The existential body expresses personality, identity and self-image. All participants indicated that they have a strong personality. They did not see themselves as a burden, but rather competent and appreciated in their workplace. They felt needed. They were aware of what it is like not to be able to participate in life on the same terms as those without impairments. They were used to assistive tools and did not hesitate to express demands.

The perceptual body describes perceptual changes such as impaired vision and hearing

recovery, even if they did not have a full-time job. Home tasks must be reallocated or governmental support should be sought.

trained, which resulted in regained energy and feeling good, both physically and mentally.

and energy for social events, but had to prioritize. Attending a dinner meant no energy for any social activity for the next days; physical activity was prioritized instead.

function. An impaired sense changes one's access to the world, but by using other senses one can experience the world in another way. All participants had good knowledge of their vision and hearing functions. They also had a good knowledge of tools and strategies.

The activity body is the body that learns to cope with daily activities. When vision and hearing functions change, the body must learn to do activities in a different way or learn completely new activities. The participants had passed rehabilitation and had been taught how to use strategies or tools, but many of them wanted more learning opportunities. Some had not received tools or training so they had assistance in some tasks instead. It was not uncommon for the tools to be poorly synchronized with work computers or programs.

We live in a social world, in a social body. It is not uncommon for PADSLS to isolate themselves as they have difficulties communicating above all. Most PADSLS have a small vision field and cannot see in the dark. This results in avoiding fun evening activities due to the extra efforts needed.

Conclusion

The following common findings emerged; all participants:

- saw physical training as a necessary activity for being able to work
- have worked for a long time in the same workplace
- had a good relationship with coworkers
- were proud of their skills and felt needed
- had a good knowledge of and were proactive coordinators of governmental support
- found that work had been taking much energy at the expense of the social life

The motivation is needed to invest energy in both every-day and working life. The study indicated a need to develop a Keep-the-Job program, aimed at young people who are

about to find their way into working life, but also those who have a job and are fighting to keep it. The study identified a number of aspects to be included:

- motivation course
- information on dual sensory loss and advisory service to coworkers
- training on available support schemes
- adaption and use of assistive tools in the workplace
- mapping the needs for measures in the workplace
- agreements that distribute responsibility for various measures
- opportunities to stay in good physical and mental health
- peer work

References

Ehn, M. (2020). *Life strategies, work and health in people with Usher syndrome*. [Doctorial thesis, Studies from the Swedish Institute for Disability Research 99]. Örebro: Örebro University. Retrieved from www.oru.se/publikationer

Johansson, A-B. (2017). *Se och hör mig. Personer med förvärvad dövblindhets erfarenheter av delaktighet, rehabilitering och medborgerligt liv*. [Doctorial thesis, Sahlgrenska akademien, Inst för neurovetenskap och fysiologi]. Göteborg: University of Gothenburg. Retrieved from <http://hdl.handle.net/2077/48663>

Berndtsson, I., Claesson, S., Friberg, F., & Öhlen, J. (2007). Issues about thinking phenomenologically while doing phenomenology. *Journal of Phenomenological Psychology*, 38(2), 256 – 277.

Find Meaning by Losing Everything

Natalia Kremneva told about a happy childhood, studying at Moscow State University, complete vision and hearing loss, the organization Usher-Forum, and the magazine Vash sobesednik (Your Interlocutor).

We have been in touch with this amazing woman for several years. I am always astounded by her tact, intelligence, kindness, and filigree literacy, the special style of each of her texts, whether it is a simple letter or an article.

At the same time, Natalia Kremneva is totally deafblind. Usher syndrome did the trick in her life: by the age of 40, she has sequentially lost hearing, and then vision. Natalia Borisovna still wonders how she survived then, how could she make it through the despair, fear, and the unwillingness to fight further.

Family and friends literally dragged her back into life. And soon she found a new purpose, becoming the world's only totally deafblind Editor-In-Chief of the magazine. It is the magazine of friendly communication, a bridge between those people to whose lives the darkness and silence came. The magazine of multiple hands holding on to each other.

In December 2020, Natalia Borisovna turned 70 years old. So, we interviewed her about life and time, which flows away from us, but remains in such texts, where the whole life is hidden in



**VLADIMIR
KORKUNOV**

THE DEAFBLIND
SUPPORT
FOUNDATION
CON-NECTION, PR
MANAGER, RUSSIA

V.KORKUNOV@SO-EDINENIE.ORG

the words and between them (especially between them).

Vladimir: Natalia Borisovna, I would like to start the interview with a question about your family. Who were your parents?

Natalia: I was born and raised in a very cultured, educated family, and this had an impact on my upbringing and the environment that surrounded me since childhood.

My mother, Nina A. Tsetkina (1919-1976), taught German at the Institute of Foreign Languages named after M. Toretz, which is now called the Moscow State Linguistic University (MSLU). The father, Boris G. Kremnev (1914-1990), was an amazing man — a self-made cultured person, who achieved everything on his own. By education he was a journalist and theater critic. He passed the World War II as an editor of an army newspaper. Writer (wrote biographies of Mozart, Beethoven, Schubert for the series *The Lives of Wonderful People*), translator of a play and a novel by Remarque: the play was called *The Last Stop*, the novel was *The Arc de Triomphe* (translated together with Isaac Schreiber). For almost thirty years of his life before retirement he worked as the Editor-In-Chief of creative associations at the Mosfilm studio.

Vladimir: That's amazing! And what was your childhood like?

Natalia: I had a happy childhood! Despite the endless illnesses: when I was six years old, I noticed a slight decrease in hearing after the flu, and talking about the sight, I could never see in the evening... But I was brought up as an ordinary child, practically nothing was forbidden, I played with my peers in the yard... In those times we lived in the center of Moscow, and there was a beautiful courtyard and friends, with whom I played. I wasn't bullied or teased.

My father taught me to ride a bicycle in the summer, and I drove around the country village. In winter, I used to go skating, my father insisted on teaching me, too. And it was the favorite winter hobby for many, many years! Also, I used to go to theaters with my mother. The most favorite performance, which I could watch endlessly, was *The Blue Bird* in

the Moscow Art Theater. Later, *The Minor* and especially *The Government Inspector*. And my dad and I often went to the opera. It was difficult to get tickets to the Bolshoi Theater, so we went to the opera studio.

Also, there were trips to different towns and cities. Dad had business trips, and he used to take me with him. And with my mother, we went to the doctors: to Odessa, Minsk... And after treatment courses we always went around the city, to museums. In Moscow, too. But before she took me anywhere, my mother wondered if there would be enough light, if I could see everything there. And before going to the theater, she gave me a play to read. So I read, and then watched Bulgakov's *The Days of the Turbins* (not once).



Natalia's picture as a child.

Vladimir: You have got an excellent education (though, we'll talk about it further). But usually, everything begins in childhood. How did your family stimulate your thirst for knowledge?

Natalia: Indeed, everything begins in childhood. In my preschool childhood, the main person was my dad. I never went to kindergarten, I was a homegrown child. And dad wasn't officially working anywhere at that time. He translated Remarque and led

a literature club at the House of Pioneers. And he was very much engaged in my development. It is thanks to him that I have a good, and most importantly, correct Russian speech: he kept a check on it very closely. I learned the letters early, but I had to work hard to put them into syllables and read.

He also constantly developed my memory: we learned children's poems. And then I read them with pleasure in the House of Pioneers at kids' parties: I liked to perform together with other children.

It was my father who tried to make sure that I was not diffident, he developed confidence in me. He convinced my mother that I should go to school alone when I went to the first grade to a common public school. It was located across the street, trolleybuses and buses ran along, and there were not so many cars in the late 50s. My mother was afraid to let me go alone. But my father insisted. He explained all the rules to me, and – go ahead! Every morning I walked alone, not feeling even the slightest fear. Many years later, my father confessed: he let me go, but for the first few months he insured me, walked behind me unnoticed. Everyone calmed down when they were sure that I was really attentive walking down the streets. This habit of walking and riding around the city on my own has helped me a lot in my life.

As a pre-school child, I had a strong fear of darkness. It was impossible to persuade me to take a walk in the evening, even taking me by the hand. But one day when I was about six years old, my father suggested going to the skating rink in the evening, where we used to walk in the afternoon. He had been trying to persuade me for a long time, promised to tell me various funny stories, and I agreed. The park was in 15-20 minutes. But we had to go through a dark alley with a single lamp burning and the dark temple. I was terribly afraid, but we ran through it imperceptibly thanks to funny stories and reached the park. Even from a distance, I saw the Skating Rink sign shimmering with colorful lights, and then I heard music, a skating rink flooded with light, and beautiful couples whirling in a dance. It was so great! Since then, I have not even thought about my fears! And I used

to whine, "Let's go to the skating rink, let's go..." I wanted it exactly in the evening.

Vladimir: And what kind of books did you prefer? Can you remember your favorite ones?

Natalia: For me, reading was rather haphazard and, as I now understand, scatter-brained. Of course, as a child, I loved fairy tales and all the books by Korney Chukovsky.

Dad read a lot of books out loud to me, and he obviously liked it. He wasn't just reading, he was playing! I listened with bated breath. Like that I listened to *The Minor*, *The Government Inspector*, and *The Treasure Island*. At home there was a huge library, I read everything. There has been, however, some embarrassment. I read *War and Peace* when I was about 12 years old. But only the part about peace. I carefully skipped the war part. And in the first year of the History Department in the group there was a dispute about how Tolstoy described the war. I was silent. They asked my opinion, and I honestly admitted that I have read selected parts, but not the whole novel.

Vladimir: Usher syndrome is a genetic disease and does not manifest itself immediately. I read that you had problems with vision and hearing since childhood. In everyday life, did this cause a lot of inconveniences?

Natalia: This diagnosis was made to me quite late, at the age of 26. And before that, they wrote separately: retinitis pigmentosa and auditory neuropathy. Just because nobody knew the Usher syndrome in the 50-60s of the last century in our country. But this does not change the fact of the disease.

The field of vision gradually narrowed, and visual acuity began to deteriorate very early. I adapted myself. For example, once I ran into a bucket left by a cleaner in the school corridor, I began to walk carefully, did not run, learned not to drop things on the street, in the subway, knowing that I could not immediately see them and pick them up.

Until my 15th birthday, we lived in a communal apartment, in a beautiful house in the center of Moscow. We had the smallest room

in a 3-room apartment. The only way I could read was by sitting in the corner of the sofa and putting a desk lamp on the back of it. I was not allowed to turn on the gas heater in the bathroom, nor I was allowed to light the stove in the kitchen.

But as a child, the field of view was still sufficient: I played with the children, there were no special difficulties. It has been gradual: the older I grew, the more problems I had. I started to spill the tea out the cup. Then I adapted to do this by holding the cup upon the sink in my left hand, hanging it in the air, and almost never spilling it. No one taught me: I tried to come up with a solution myself. I learned Braille early, aware that I would need it. Hearing was easier, because in the last year of school I got a very good Danish hearing aid: with it, I could hear almost 90%.

Vladimir: Did you have many friends then?

Natalia: As I already mentioned, in childhood, my social circle was the kids of Moscow courtyard. Typically developing children about my age, with whom I played all the children's games. When we lived in the summer house (Russian dacha), there were friends in the village, my parents were friends with their parents. We had such a "dacha society": we gathered in the evenings in someone's garden or on the veranda, drinking tea; the adults talked a lot about politics, literature, new films, performances, and we, the children, about something of our own... In the winter we did not meet often. But we always invited each other to the birthdays.

Generally, the issue of friends of a child with special needs is very important, but for some reason, no one really devotes efforts to it. While children are small, they play hopscotch and ball, so there are a lot of friends. As they get older, typically developing peers become distant towards a child with special needs. This is an unavoidable pattern. But this is also sad: empty spaces can appear. Therefore, it is very important to create a social circle for a child like that, to select friends who will be close to him in adulthood. This is very difficult, but necessary! I didn't have that as a kid.

Vladimir: Did you graduate from a public school or did you have to go to a special needs school?

Natalia: Of course, I started first grade at a public school. Forty kids to a class. I was the only girl who had disabilities. I used to sit at the first desk. However, I did not write a single dictation as the teacher uttered it, standing next to me: I couldn't hear that well. I wrote my own text, but it was more complicated. Only my teacher and my mother knew that I wrote something completely different. The teacher checked me, gave me grades for my work, and always praised me. She did everything to make my classmates help me.

But in high school, the teachers changed, it became difficult for me. Moreover, I appeared inclined towards the humanities. Math, physics, and chemistry were completely beyond me, I didn't understand anything. And our class began to fall apart: the families of my classmates started getting new apartments, move out of basements and barracks. Our co-op house was also being built, and we were going to move. And then my parents decided to switch schools. They chose the school for hard-of-hearing children in Sokolniki in hopes that it would be easier for me to study there and I would have my own social circle.

I was accepted. But the relationship with the Deputy Head Teacher and with some other teachers was not so good. In addition, just in those years, my vision quickly decreased, I was withdrawn. In all the exact subjects, the grades were bad, and I was scolded for them in front of the class. That made me even angrier. In a word, only the lessons of literature, Russian, German, and a couple of other subjects somehow heartened me. Psychologically, it was an extremely uncomfortable thing. At home, I was a smart, intelligent, cheerful, sociable girl with a sense of humor. Once inside the school, I was becoming gloomy, sulky, always waiting for a trick and ready to snap, be rude, or cry, such a resentful girl waiting for ridicule and disregard.

I just wanted to say goodbye to school as soon as possible. The school provided an excellent education, but regarding morals,

humanism, charity, tolerance – alas... Then all these values were left behind the scenes.

Vladimir: How did you choose the History Department of Moscow State University?

Natalia: I wasn't going to go to the History Department. I wanted to be just a journalist and nothing else. For some time, I even used to visit seminars at the Central House of Journalists (my father arranged it): I liked them very much.

But when I graduated from school and announced that I would enter the faculty of journalism, my father said categorically, "No, you can't be a journalist, you can't go on business trips, meet, communicate with a lot of people. They just won't accept your documents. You need to choose something else".

Perhaps for the first time in my life, I was told directly and firmly: this is not available to you. And, what was especially offensive at that time, it was said by my father, whom I loved endlessly, idolized, and used to believe every word he said... Later, I realized that he was right, he did not want any unnecessary emotional scars. I gathered everything I wrote, put it in two bags and threw it in the trash! No spells no!

We decided that I would enter the History Department: that year there was the smallest number of students competing for each place.

Vladimir: How did you spend your student years at Moscow State University?

Natalia: It was very difficult to study at Moscow State University. Having realized that I couldn't listen and take notes at the same time, I decided to listen and remember. This was possible thanks to an excellent memory. I took lectures from my classmates and copied them.

It was difficult to participate in seminars when several people were talking at the same time, interrupting each other, arguing. With a hearing aid, it was difficult to catch and understand the essence, there was noise.

But honestly the biggest problems I caused myself. All my youth was unspeakable

self-doubt. The only thing I did was trying to hide my impaired hearing and vision. I was scolded for it, but it was useless. Sometimes I got into dangerous situations. I was afraid to cross the wide Leninsky Prospekt without a traffic light, where I often went to the store, but I could not ask anyone for help. I just waited for someone to cross, and I ran across with him, attaching beside.

At MSU, problems with vision manifested themselves more often than problems with hearing, and they were not always resolved immediately and painlessly. I remember when I had the test in German. We had to read and translate the newspaper article into Russian. And I didn't see the newspaper font, it was too small. I asked the teacher to give me this text typed on a typewriter or write it by hand. She refused and did not accept the test. I visited her twice more. The same thing: read the newspaper! And without this test, I was not allowed to take exams. I cried, but I didn't tell my parents.

Finally, after another useless pleading, my indignant friends went to the dean. The dean was a good man, a war veteran (he had no arm), he called the teacher and told her to take the test. She put the pass in my credit book without testing me, flung it to me, and we parted. But this was probably the only case of straightforward ill-will. Generally, everyone was very attentive. My most favorite young teacher of the ancient history of the East taking the exam, offered to read aloud herself the questions of the ticket.

Vladimir: We are coming to the critical point that has divided your life. I mean 1990 when Usher syndrome did its thing, and you first completely lost your hearing, and then your vision. How can a person get used to this, when the light and sound were "turned off"?

Natalia: Total deafblindness, that is, the complete loss of both vision and hearing, is a grievous tragedy. In my opinion, the most important thing is the support, the help of loved ones. Their attitude and ability to rebuild the life of a deafblind person so that he continues to feel love, his need for loved ones. It is impossible to get used to deafblindness. It is necessary to accept it, to adapt to live in new conditions!

I always knew that my vision would deteriorate, although the doctors in those years did not tell anything. But I was completely unprepared for the fact that my hearing would suddenly and irrevocably decrease and no device would help me. And that's exactly what happened: one morning I habitually put on the device... I heard the usual mumble of the radio in the kitchen. I heard the sound of running water. But when all this was "turned off", I could not understand the question addressed to me... I heard the voice and did not understand the speech... No matter how I turned the volume of the device, it gave nothing but a whistle.

It was my huge mistake: the hearing aid helped well, and I did not make an audiogram. Later I found out that neither did many of my friends with Usher syndrome. And this is dangerous because you miss the moment when your hearing begins to decrease. I didn't want to believe that the problem was not the hearing aid, but me. I got a new Danish device, but it almost didn't help me.

I still don't know how I survived then, there was everything: despair, fear, endless tears, just the refusal to live. It didn't last long, but it was quite intense. And the main question was how to communicate? The main thing was that I worked for many years in the Deaf community, I knew that one can write on the palm of a hand. This became the main way of communication. Then cheerfulness and optimism defeated. I got a job. I was very tired, but I was among people all day, there was no time for emotions. And it was necessary to earn something. Then I spent a month and a half of rehabilitation in the Volokolamsk Center, in the department for the deafblind, where, without exaggeration, I was returned to active life.

Vladimir: In the West, deafblind people often talk not about losing vision and hearing, but about finding something new in life. Has there been any gain after the loss in your life?

Natalia: I think I had and still have some inner freedom. I somehow imperceptibly got rid of self-doubt. While I was able to hear and had some vision, I constantly tried to hide my problems. And when there was nothing left,

there was nothing to hide. And I started to talk about my disability to see and hear. The only excuse is youth. It is very difficult for a young attractive girl to say, "I can't hear well, repeat...". I became myself.

Vladimir: I want to ask about the Usher Forum that appeared in 1998. You were among its founders. Tell us how and why this organization was created? What did you do in the first years of its existence?

Natalia: To answer your question, I will tell you about an event in 1992. Then the international festival of young individuals with disabilities was held in Moscow. And a group of children with Usher syndrome came from England, led by Mary Guest, a very well-known specialist in the world, who was engaged in social support and research on the issues of people with Usher syndrome. As part of the festival, a conference on Usher syndrome was held. We got to know each other, talked about ourselves, our problems, and how these problems are solved. You know, the English were so open, so natural, so frank about everything. It felt like they were used to sharing, talking about what they care about, about their experiences. And we sat uptight, tensed. The organizers took a lot of effort to make us, the Russians, talk. We could not and did not know how to talk about ourselves.

We also learned what they do in England to support the individuals with Usher syndrome, they even have their own organization. They gathered, had fun, communicated, and what's most important received information about Usher syndrome and psychological help, they had services of interpreters. We could not even think of such a thing in those years.

I managed to attend this festival for one day, but it was enough to get excited about the idea of such an organization for the individuals who have Usher syndrome in Russia. I told Irina Zuckerman about this idea, she supported and introduced me to her colleagues in the laboratory of the Institute of Correctional Pedagogy – Tatyana Aleksandrovna Basilova and Irina Vladimirovna Salomatina. Then we began to

look for like-minded people among the people with Usher.

We held the first panel discussion. Irina Salomatina started publishing the newsletter Usher-Forum. The first issue of the thin magazine was published in 1996 and turned out to be so interesting! For the first time, many of us learned about Usher syndrome, got acquainted with the life stories of others. Even before the official registration of the organization, we began to hold events. I still remember the first excursion to the Pushkin memorial flat, where I dusted all the exhibits. We were allowed to examine everything with our own hands! These excursions were arranged in advance: each of us had an interpreter. These were student volunteers, whom Irina and her assistant specially trained. Many of them have become excellent professionals working with the deafblind.

More and more people with Usher came to our meetings. And in February 1998, we officially created our organization. I have often been asked: why do we need a separate organization for people with Usher, how do their problems differ from other deafblind people? Usher syndrome is one of the main causes of total loss of vision for the deaf, that is, it leads to total deafblindness. And a person needs more support, especially psychological one: they need special services, special events, they need help for families. And, of course, the sooner a deaf person with Usher syndrome begins to adapt, learn tactile sign language, new technical tools, and Braille, the easier it will be later... All this is easier to do if people are united.

Vladimir: Your main creative brainchild, the magazine Vash Sobesednik, appeared in 2003. Tell us how you managed to make your childhood dream come true.

Natalia: When we created the organization Usher-Forum, and I took rehabilitation courses and learned to type on a typewriter by the blind method, I began to write many articles, first of all, for the newspaper Mir Gluhih and the magazine V Edinom Stroyu, as well as in the newsletter Usher-Forum.

But one day I was sent an English magazine Rainbow about the life of the deafblind in the

UK. It was printed in Braille in English, and I couldn't read it. But I sent the magazine to a blind friend, and soon he sent a translation of several articles. It was an extremely interesting magazine! So homely, with simple, even funny stories told by individuals with disabilities themselves. No problematic materials, but a lot of useful information and readers' letters about their families, hobbies, friends and helpers. A kind, bright, positive publication. I told my friends Elena Volokh and Nina Solovtsova about it and suggested that we try to do something similar. We had absolutely nothing but desire, no computer equipment, no publishing experience, and (most importantly!) funding.

And then I invited Irina Salomatina to talk. Irina understood everything and supported us, promising to find volunteers, negotiate with the printing house and find money for publishing expenses.

And work has begun. My kitchen became an editorial office. We all came up with the names of notes and headings. When the work was finished, each received her own homework until the next week. Then Nina rewrote all the texts, and exactly on time I gave Irina Vladimirovna the first issue of our magazine. The volunteers typed, made the layout, and the issue was printed. That's how our magazine appeared, and it is still alive!

What a delight it was, how we were thanked for the first number! And readers began to write to us actively. And we, having corrected the letters, published them and put the author's name. Do you know how it raised their self-esteem? Our readers-authors showed the magazine with their article to the relatives. Here, my article has been printed! So, someone is interested in me! When 5 years later there was no money for the release of the anniversary issue, I was rushing around Moscow in search of the necessary amount of money for the printing house and in despair wrote, "That's it! I can't do it anymore, we're closing the magazine". In response, pleading letters flew, "Do not close it, this is our bridge to each other!"

Now, many deafblind people have the Internet, but not everyone, and not everyone can use a computer. But even those who

OPINIONS AND INTERVIEWS

can always go online to continue to read the magazine, ask when the next issue will be published, and send interesting notes and links. The magazine is in demand!

It is read in Moldova, Ukraine, and Kyrgyzstan, moreover, in Braille versions. Some specialized universities have also signed up, of course, specialists read it, and parents of children who have vision and hearing loss.



The issues of Vash Sobesednik magazine

Vladimir: In 2014, the Deafblind Support Foundation Con-nection was established, and now Vash Sobesednik is published with the support of the Foundation. Tell us about the magazine's plans for 2021.

Natalia: Yes, with the advent of the Con-nection, the magazine began a new life. Thanks to the support of the Foundation, it has become prettier, up to date, and

attractive. But it remained the same kind, positive interlocutor and friend for many.

In each issue, we talk about the activities of the Foundation, and since 2018 about the Association Con-sent, its projects and programs. This will be one of the main topics in 2021.

The pandemic has changed lives, leisure centers are not working at full capacity, there are almost no face-to-face events and meetings. It has become more difficult to get information from the regions. But we will still find it. In the next issue, we will tell you about the online forum of regional activists that took place in December.

Vladimir: It is clear that your editorial work is successful. Can you personally be called a happy person?

Natalia: I am a modest person, I do not like loud words about myself. But, I think, yes, you can say so about me – a happy person! I had a happy childhood, wonderful parents who gave me everything they could: a good upbringing and education. I had a wonderful youth: meetings and communication with a huge circle of interesting people, hobbies, love for theater, cinema, travel. There were friends.

And even after a complete loss of hearing and vision, thanks to my friends I found myself in another business, found the meaning of life in new conditions. I had a lot of love, the warmth of a loyal, reliable person. And there is something that I have managed to find meaning, having lost everything: my magazine that gives me the strength to overcome difficulties.

Memorable Moments in Dbl

Memories are special to everyone. As a member of Deafblind International (DbI) I have so many wonderful memories of the growth of this very special organization.

Listening to some of the early founders, it was clear that they wanted the very best opportunities for children with deafblindness. There have always been individuals identified as deafblind but in the 1950's more children were seen in programs and with little available information, a small group of individuals from Europe and North America started communicating through the mail. The first opportunity to meet was in 1962 at Condover Hall in Shrewsbury in the UK. Imagine the excitement and joy to be able to talk face to face with colleagues and share stories about their work. Sharing experiences in a non-competitive way has always been at the heart of DbI. After this gathering, other organizations arranged small conferences. The first step toward a more formal organization of DbI took place in 1976 at the conference in Sydney. The group was eager to share knowledge and information about working with children with congenital rubella syndrome. Little was known about educating the children. This group of children, I believe were the catalyst for the expansion of services to children with deafblindness. We owe so much of what we know today to this group of individuals. They taught us about the need for communication, how to wait for a response and the importance of movement. About 200 people attended this conference and for me this is where I was introduced to many of the early leaders in our

field. I remember how welcoming everyone was. Even though it was the first time to be around colleagues in the field, I felt like I knew these people for a long time and I felt supported. It was during the conference that the group met officially as a sub-committee on the Education of the Deaf-Blind. This was part of the International Council for the Education of the Visually Handicapped (today known as ICEVI).

The first world conference was held in Hanover, Germany. The participants stayed in various agencies and hotels around the city. You meet new people and travel together to the conference site. At this time the attendees were primarily from Europe and North America. The people coming from developing countries were very few. Throughout the developing world it was estimated that fewer than 250 children with deafblindness were receiving services.

During the early years DbI offered its members opportunities to attend conferences and there was a small newsletter that was circulated. The funding for other opportunities was limited.

Interest continued to grow and conferences in New York, France, Sweden, Argentina, Portugal, Canada, Brazil, Western Australia, Romania and the Gold Coast, Australia brought together professionals, families and



**DR BERNADETTE
KAPPEN**

DBI BOARD
MEMBER

[BKAPPEN@NYISE.
ORG](mailto:BKAPPEN@NYISE.ORG)

OPINIONS AND INTERVIEWS

an increasing number of deafblind people. Inclusion in activities was a major goal.

The conferences provided an opportunity for sharing information and learning. It also provided structured time for the members of Dbl to develop the organization. As interest grew, there was a desire to be independent rather than a sub-committee of ICEVI so at various conferences committees worked on developing the structure for Dbl. After a strategic plan in the 1990's the current structure as we know Dbl today was formed: ManCom and the Board. With the new structure, funding followed and has allowed Dbl to grow and provide more to its members. Another change around this time was the spelling of deaf-blind to deafblind. This change captured the uniqueness of the disability.



On the right Mariana Suolsami, President of IAEDB in Sweden Conference with a participant from Argentina (1991)

As the participation increased, the need to have a focus on not only children grew. The members wanted to discuss the needs of adults. An exciting step forward for Dbl was the development of parent and family groups. The importance of knowing what the families needed and wanted helped the professionals to provide better services.

The members of Dbl have used their influence to have deafblindness identified in Europe as a unique disability. This has also happened in other countries. It is sometimes difficult to influence government officials on your own, but with the strength in numbers from Dbl members so much can be done.

The creation of programs over the years have been with the support of other colleagues. In 2006, the Asian conference in Bangladesh opened eyes of the officials to the fact that something needed to be done. I remember sitting in the audience as colleagues and individuals who were deafblind from India and other countries shared their stories. Throughout the years having colleagues share their stories has been helping individuals around the world to begin to develop programs.

The expansion of services can be seen in each issue of the Dbl Review. Reading the stories motivates others to improve their programs and for some to increase their services. As the children in school started to age out, programs shared information on transition to adult life. Dbl Review has encouraged many of us to further develop art and cultural programs. When you see the talent displayed, you know you have to give the children and adults more opportunities to be involved in this aspect of life. Sharing was the key to success of Dbl.

The networks have grown over the years as the members wanted to connect with others doing similar work. The conferences is a mean of connection, but the networks give members additional opportunities to focus on their special area of interest. For many years the Acquired Deafblind Network has been hosting extremely successful conferences. Currently we see the joy that young people experience when they participate in the Youth Network.



Stan Munroe in the left standing with a group of people during Canada Conference in 2003



Deafblind Youth Network

OPINIONS AND INTERVIEWS



Members of the Scientific Committee working for the World Conference in Gold Coast, Australia 2019



A group of Canadian delegates at the 18th Deafblind International World Conference. Ontario, Canada.

Throughout the history of Dbl, communication has been such an important focus for children and adults. The Communication Network worked tirelessly to share information and their work resulted in a series of booklets. Communication for the individuals who are deafblind has been the key but I also believe that communication is what has made the organization strong. As the years have passed, it has become easier to communicate through email and social media. The Internet helps to connect us to research and information that either didn't exist or was very hard to find. Providing more information in Spanish helped to connect the members and this was made possible for many years with the support from ONCE. Currently, the material is also available in Russian.

I remember that Dbl started from a small group of less than 50 dedicated people, 8-page newsletter and opportunities for few

people to gather at conferences to the Dbl of today.

The increased use of social media keeps us connected on a regular basis. The sharing of information and being transparent in the activities help to unite us. So, what is special about Dbl? When I think about this question the words support, knowledge, caring, friendships, expertise and fun come to mind. I see these words in action when we gather for conferences and when I read the Dbl Review. I think this spirit should always be part of the organization. When you meet a Dbl member you speak the same language and you never have to explain what do you do. The bond between people who work in the field is so strong. I have never felt this with another group. As we expand the organization, this should be something we always strive for. Everyone should feel welcome and supported. Dbl is the ongoing connections we have around the world.

5 Great Achievements that Should Make Us Proud



TONY BEST

UK

TONYBESTDB@GMAIL.COM

As I read the last issue of Dbl Review, I realised that vast changes have taken place within the field of deafblindness very recently but there are also some enduring characteristics. Many of these changes are improvements; many of the enduring characteristics are assets, not liabilities. But it feels important to remember this heritage, so we can recognise and celebrate the underpinning values of the field. From where I'm standing now, I can look over 50 years back and recognise 5 characteristics. All of them are achievements that we should be proud of.

Parents & Families

These were parents, and then families, who started much of the international work in deafblindness and this, I believe, is unique to the field of deafblindness and Dbl. In the 1950s, parents struggled to learn how to help their child and used to write down every scrap of information they collected to share with other parents. It was only later that teachers and doctors joined in and developed a body of knowledge. Pioneers like Peggy Freeman and Rubella Group in the UK made contact with parents in Canada and a network developed. And this inclusion of parents and families remains a valuable and valued characteristic of our work. In 1989, Dbl adopted the resolution

that all their further conferences must be accessible equally to professionals and families, and that is now a tradition of our field.

Their role was changed from advocates and activists (Peggy would talk about being an irritant that you cannot ignore) to being equal partners. Today, our practice has moved further to ensure that deafblind persons themselves are central to service design and delivery and, moreover, we are led by them. We have created a related kinship and should remain proud of this element of our culture and strive to ensure parents and families remain an integral part of Dbl.

Identity as a Disability

It was only in 1991 when the word Deafblind was introduced. Before

that the field talked about people with Rubella, and then the

deaf-blind, and later the multi-sensory impaired.

The first international conference (not under the name of Dbl as that name was adopted in 1999) was held in 1964 in Conover, England, but for the next 30 years there was a constant struggle to describe whom the field included and identify content and approach. Dbl was absolutely essential to resolve that struggle and gradually build up a shared vision of deafblindness, that separated it from hearing impairment, visual impairment and mental disability. This was a formidable accomplishment leading to recognition

Staff Development

When I became interested in the education of deaf/blind children in England in 1960s, it was not possible to receive any training at any British school or university. So, I joined the fabulous teacher training course at Perkins School, and had an incredibly enjoyable and valuable experience that has been helping me throughout my whole career. How different it is now! A field of study has been identified and we can describe the skills, knowledge and attitudes that are needed to support people with deafblindness. This has moved us from practicing folk art (using ideas as they occurred to us) to evidence-based practice. The development opportunities

Respect Pioneers

The field of deafblindness has traditionally evolved through building on the work of each generation. Some other fields related to disability have changed previous ideas and practice through revolution and dismissing, often with vigour and passion, and this has resulted in fragmentation, hostility and extremism. It's not the same for deafblindness.

At the international conference held in 1971, I remember a session with a presentation on how we (the centre I worked in) were trying to use objects to represent activities rather than use deaf sign language. In the same session, speakers from East Germany gave their ideas on using fixed daily routines, and Jan van Dijk described his idea about creating

of deafblindness in the UN Convention on the Rights of Persons with Disabilities in 2007.

Today, many countries are moving towards a more generic approach, and even avoiding the label of deafblindness. To many of us involved in the struggle for recognition this may feel like a mistake. Dbl has found a way of keeping the label and using networks to support the vast range of members' interests. As for me, this feels like a good way of building on the tremendous accomplishment of creating an identity and a separating field of study.

are available in many parts of the world now for a range of professionals (not just school-teachers) and help them to support people with deafblindness of all ages.

As for me, the most important element concerned the introduction of research and the use of evidence to underpin developments and verify practice.

This is a remarkable achievement of the past 40 years and, looking through Dbl Review, it is clear that Dbl still has a vital role in providing training and development opportunities to those colleagues who are in the field.

attachments between a deafblind child and his/her carer. These were new ideas, but we were the ones whom they listened to. The colleagues with many years' experience listened, questioned, discussed these together, and new practices gradually emerged.

The field of deafblindness, I believe, is characterised by respect for institutions, organisations and individuals and a recognition of their formidable contribution to the growth of knowledge and improvement of practice. I suspect that even today many people will recognise the names of significant pioneers, for example, Waterhouse, Robbins, Collins from the USA, McGuinness and Treffry from Canada, Jan, Norman, Peggy, and Ton from Europe.

■ OPINIONS AND INTERVIEWS

That is simply the way we do things here. Learning from each other as we struggle, with passion, to find better ways. And Dbl is

Multi-Disciplinary

From the beginning, people with different professional backgrounds have been working together to solve problems and provide services. In the 1940s and 1950s, many health professionals had key roles in diagnosing and prescribing treatments. The educators and psychologists then became more central to our work, before this sector expanded, which led to inclusion of intervenors and therapists.

Everyone was welcomed to Dbl and encouraged to contribute to publications and conferences. I would go as far as to suggest that

Conclusion

2020 has shown that the future may be not only stranger than we imagine, but stranger than we can imagine. However, from where I stand now, it is heartening to look out at such a strong and vibrant field. Or rather such a strong group of people dedicated

central in showing this respect and enabling the collective learning that can ensure that we continuously improve our offering.

Dbl was essential to ensure this exchange of professional perspectives and to encourage the feedback and discussion between professionals that resulted in creative and original solutions.

In the future, there seems the possibility that researchers (already recognised through their own Dbl Network), geneticists, electronic engineers and a wider range of therapists can all contribute and join the challenge of finding better ways of doing things. The Dbl Review will continue to be one essential part of this development.

to work within deafblindness. As Margaret Mead is said to have written, "Never doubt that a small group of thoughtful, committed people can change the world. Indeed, it is the only thing that ever has." Best wishes for a successful journey!

Tangible Concepts about COVID-19 for Children with Multiple Sensory Visual Disabilities

Children with multiple disabilities and visual impairments are part of a broadly heterogeneous group in terms of their specific learning needs. They have visual impairment associated with other disabilities, such as intellectual disability, physical disability, cerebral palsy, communication deficit, syndromes, and fragile health conditions (Chen, 1995).

They often face difficulties in accessing incidental information from their environment. The lack of reliable access to information, caused by visual loss and the impact of their additional deficiencies, becomes an obstacle to the development of concepts.

The concepts are built on each other and the more meaningful experiences and memories a child has about the way objects, environment and relationships work, the easier it will be to acquire new skills and develop new ideas.

When the child realizes, for example, that putting his hand in his mouth means receiving food, he is able to understand the concept of cause and effect. Acquiring an understanding of a cause and effect concept favors the learning of others.

Therefore, when proposing activities for children with multiple disabilities and visual impairments, it is useful to determine what are concepts and what are skills. Presenting certain skills does not necessarily mean

understanding related concepts (Miles & Mclethie, 2008). For example: a child is able to take the plate and cutlery to the sink, but does not know that he needs to wash them after use.

This type of learning happens naturally for children who see and hear, but for children with multiple disabilities and visual impairments the acquisition of concepts occurs in a concrete, meaningful and continuous way.

Offering concrete experiences, based on everyday situations and in a natural way, is a viable way to provide the understanding of concepts in gradual expansion (Miles & Mclethie, 2008).

Based on such aspect, the things proposed in this work are the cards of tangible symbols aimed to favor communication and the formation of concepts about the pandemic of COVID-19. There are five cards, containing objects nailed with velcro and legends written in Portuguese, in ink and in Braille, which are described below.



FLAVIA DANIELA DOS SANTOS MOREIRA

BENJAMIN CONSTANT INSTITUTE, PROFESSOR, RIO DE JANEIRO, BRAZIL

FLAVIAMOREIRA@IBC.GOV.BR

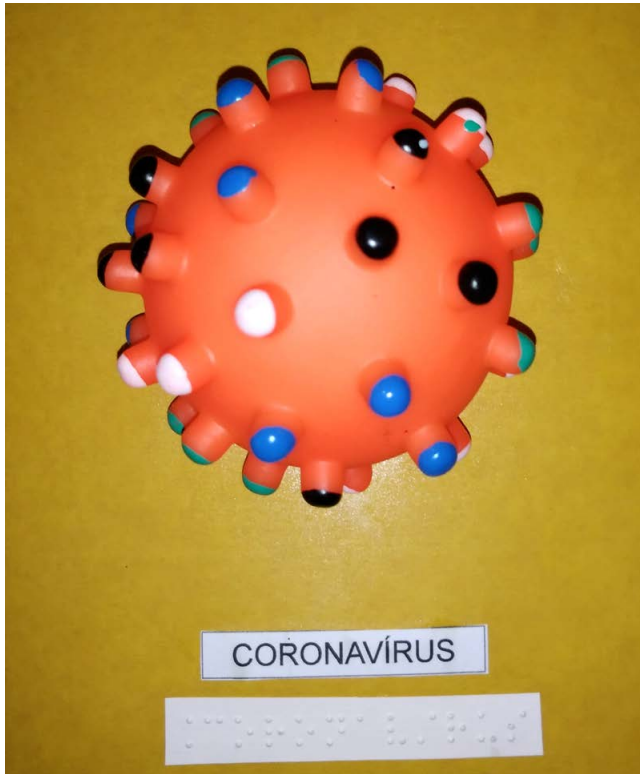


Fig. 1. Coronavirus card. Source: Prepared by the author.



Fig. 3. I Need to Wash card. Source: Prepared by the author.

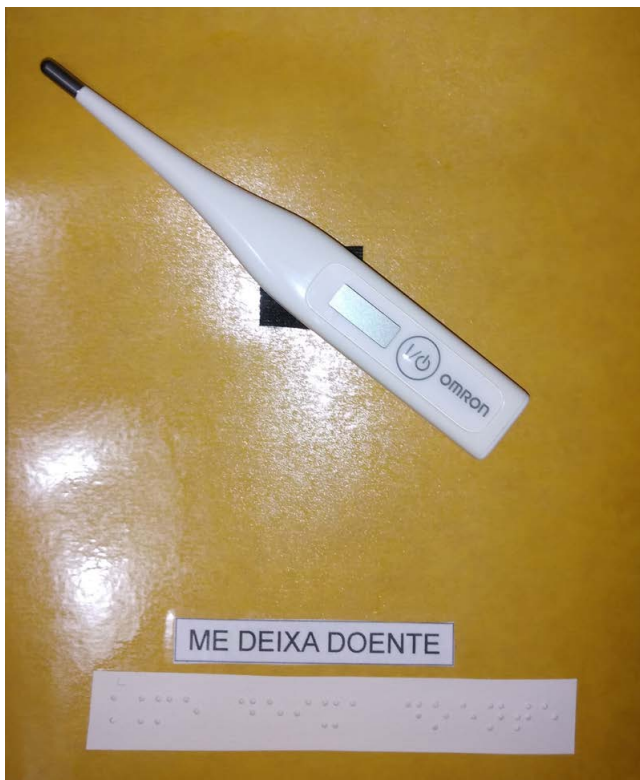


Fig. 2. Makes Me Sicking card. Source: Prepared by the author.



Fig. 4. The Hands card. Source: Prepared by the author.

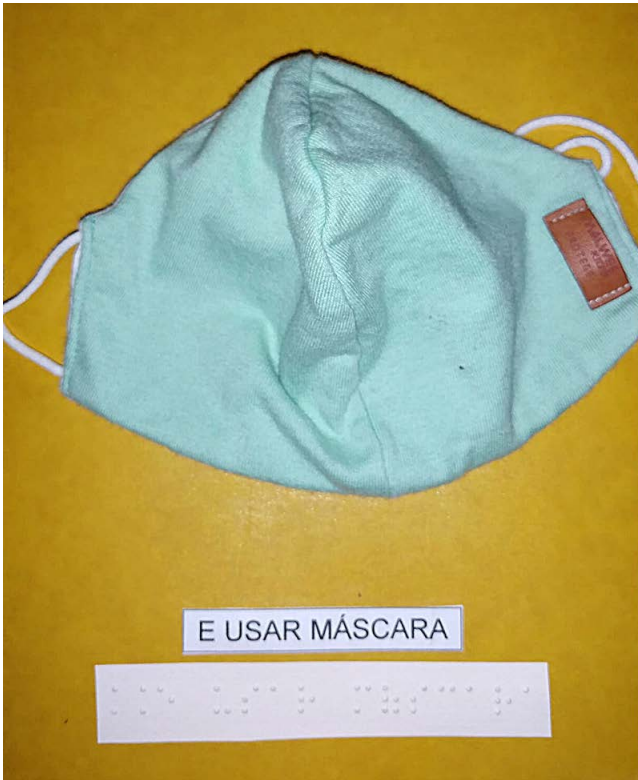


Fig. 5. And Use Mask card. Source: Prepared by the author.

As it has been mentioned, all objects were attached to the cards with velcro to be touched and unfolded by a child. Before using the cards, children should explore and handle the attributes and functions of these objects, as shown in Figure 6.



Figure 6 – Box with loose objects. Source: Prepared by the author.

After learning the objects, they can be associated with situations that represent them:

- when talking about Coronavirus, the ball serves as a reference
- the thermometer is used to represent that this virus causes a disease and the person may have a fever
- the tap and the rubberized hands indicate the importance of washing hands
- the mask represents the need and importance to protect against this virus



Fig. 7. Cards of tangible symbols forming a complete sentence.

These objects must be handled and their functions must be explained within the contexts that represent them. After the child knows the objects, they can be nailed

to the cards to form the following sentence in Figure 7: CORONAVIRUS MAKES ME SICKING, I NEED TO WASH HANDS AND USE MASK.

■ EXCHANGE OF EXPERIENCE

Even if a child still does not accept to use the mask, it is important that he or she handles this object and knows its function and importance. As tactile exploration does not happen spontaneously, it is important to create opportunities to talk to the child about the

pandemic and about ways to protect against this virus.

These cards are expected to be useful for children with multiple visual sensory disabilities to understand, in a concrete way, some concepts about this pandemic.

References

Chen, D. (1995). *Who are Young children whose multiple disabilities include visual impairment?* In: Chen, D. & Dote-Kwan, J. *Starting points: instructional practices for Young children whose multiplex disabilities include visual impairment*. Los Angeles, CA: Blind Children Center.

Miles, B. & Mcletchie, B. (2008). *Developing concepts with children who are deaf-blind*. The National Consortium on Deaf-Blindness.

Accessible Virtual Learning for Children with Extensive Support Needs

Virtual learning started out as an idea that would only last for a few weeks, and then a few months, and now it has almost been a full-year endeavor. While working with students with extensive support needs, you may rely on tactile cues and objects, or American Sign Language (ASL) and Braille. You may also need to use techniques such as hand-under-hand or physical prompting during activities. Due to Covid, the professionals of this field needed to improve their technical game and find creative ways to make meaningful lessons for students who heavily rely on touch through a screen. This last year I have worked with a variety of students, with differing abilities, and their team on how to make sure these students don't fall behind. Although the world feels like we are on pause right now, we must persevere and push forward to provide real and practical solutions to virtual learning. Thankfully, there are strong educators out there finding creative ways to support everyone, because our students still need to learn.

I have observed multiple virtual classes during the previous year and have been impressed with everyone and their ability to adapt. One student's mom went above and beyond by setting up a workstation for her daughter. The dining room table became the classroom for this student and this student has 5+ screens to maneuver with her mom throughout her school day. Her main screen is in front of her, and it has the teacher and interpreter highlighted or pinned. A screen to her right shows all of the students who are also in the class, as inclusion is a priority for the mother and her

daughter. The third screen is the biggest screen, and it is propped up above the first screen where the teacher and interpreter are pinned. This screen is prioritized for worksheets or lesson slides, so they can be magnified to accommodate her vision needs. The final two screens are tablets. One is set up to be the primary audio so there is no messy feedback problems. The other tablet is directed at the student and used to help facilitate specific therapies that work on gross motor skills. This whole system is unique to this student and works for this



KAYLA COBURN

CALIFORNIA
DEAFBLIND
SERVICES

[KCOBURN@SFSU.
EDU](mailto:KCOBURN@SFSU.EDU)

EXCHANGE OF EXPERIENCE

family's situation. However, multiple screens would not work for everyone.

Another team I work with has found additional ways to make virtual learning meaningful for their students. They were able to develop this because the team is very communicative and collaborative. The teacher has ongoing weekly plans that are repetitive, tactile-focused, and modified appropriately per student. The teacher puts students into groups, has equipment for parents to pick up every couple of weeks, and if something does not work, they work as a team to find a solution. One of the students who is deaf-blind was not actively participating in some of the activities. A team member remembered how the student preferred playing with a light box during her therapy sessions. When virtual learning became frustrating for this student, they changed her picture exchange communication system to translucent cards that can be used on her light box. This student can now remain attentive for an entire 30-minute lesson. This team came together to make these virtual lessons accessible and fun for this student (and with a mom who was able to support her full-time, they made it happen.)

However, we know that parents can't always be there. Other teams have had to accommodate to a working parent's schedule. A family who I worked with and who has two children with extensive support needs, had to find creative solutions on how to use the children's one-on-one aides virtually and how to use zoom to its full potential. The teachers had to improve their technological skills to better support their students with vision and hearing needs. This team would magnify the page, connect the computer to a speaker to make their voices louder, and give the assignments to the parents beforehand so they could make any changes if necessary. This was another team that had to try multiple accommodations before finding what worked. It was a frustrating process

for the parents, teachers, and students, but within a few months, their parents were able to step back from the screen and let their children attend their virtual classroom independently.

Lastly, there was a team who had to use all of their resources to provide a successful virtual learning experience for their student. The parents have multiple children, English is their second language, and their oldest child has no eye sight and very little hearing with hearing aids in. This student could not attend a virtual class and his school goals were not possible to be achieved at home. This team had to change all of his goals to activities he could do at home. At school his goal was to walk to the cafeteria and pick out his lunch independently. At home, this changed to organizing his place setting and food for his lunch. The activity was still preparing or receiving food independently but done in a completely different setting. This was another challenging schedule to adapt to as his mom and dad had jobs and multiple children, not to mention assisting with virtual learning in a language they weren't confident in. Thankfully, the team made the effort to support the student and the family and gave them equipment to use at home for more tactile work activities and lessons, plus information translated in their native language.

All of the examples above concerned the students with varying abilities, parents from different backgrounds, and a variety of ages and classrooms. The one thing they all had in common, was a team that worked together to find a successful solution for the student to access virtual learning successfully. The virtual learning was a huge transition for all of us, but the educators, families, and therapists came together to make it work for their students. I am thankful to be able to observe and assist these phenomenal teams as they make learning meaningful to students.

Rise Like the Phoenix

The year 2020 was marked globally by the COVID-19. Guatemala was no exception and with the previously existing levels of poverty and inequality, coupled with a precarious health system, among other unfavorable aspects, the impact was profound, evidenced by the loss of thousands of jobs, business closures and in the field education for school dropout. This situation notably affected the population with disabilities, so much as some organizations that provide services to that population were forced to close.



CARMEN LUCIA GUERRERO DE PRADO

FUNDAL,
GUATEMALA

CLGUERRERO@FUNDAL.ORG.GT

The Fundación para Niños con Sordoceguera Alex (FUNDAL) was not immune to the impact of the crisis caused by COVID-19, presenting obstacles in different areas, mainly in the financial aspect, where there were even situations of reduction of personnel, which had repercussions on their daily work. This situation added to the complexity that it represented for the foundation, continuing to provide direct care to users, adopting sanitary measures to avoid the increase in infections such as confinement and social distancing.

FUNDAL, being the only private non-profit organization that has served the population with deaf-blindness and multiple disabilities in Guatemala for 23 years, made the decision to rethink its activities and adapt to the new normal during the crisis, like Phoenix, to take the situation as an opportunity for change. When it was believed necessary to close the institution, as happened with many companies and organizations that could not withstand the impact of the crisis, it emerged as a light at the end of the tunnel, a spark of

hope, translated into a reengineering of the main activities, which allowed to continue its operation with the valuable help of the team of collaborators and volunteers, as well as the Government and International Cooperation. The process involved, in addition to reinventing the way of providing services, maximizing the potential use of existing resources.

In the framework of the analysis, it is also possible to appreciate and highlight some characteristic situations from the effort that has arisen from the families, who have had to transform their houses and other spaces of coexistence into classrooms. Likewise, despite the negative impact they experienced on their income, they found themselves in the need, in the best of cases, **to share the few electronic devices they have** so more than one member of the family could use it and thus remain connected, to support services. The Internet and electricity do not reach all homes, so they have had to face the barrier of access to this type of services, which are considered basic in the new normality.

EXCHANGE OF EXPERIENCE

Parents have had **to assume the direct role of professionals to provide habilitation and rehabilitation**. The process wasn't easy at the health, education, economic and, above all, emotional levels.

The plan that was carried out and organized as a team so that no one would be left behind, considered an analysis of the situation of **each family**, both users and collaborators, **remote monitoring**, and **weekly accompaniment**. On the other hand, the educational team was creating different communication mechanisms to bring the families the different services, considering the specific conditions and realities of each one.

For families and students, to continue receiving educational services, it was necessary to explore the diversity of communication mechanisms, product of this, synchronous sessions were provided through Zoom, video calls, text messages (WhatsApp, Facebook Messenger, cell phone), private Facebook groups, preparation of printed guides, and delivery by mail. Everything was adapted so that families and students could access to the services, which required effort, dynamism, and creativity, but above all a coordinated teamwork where the attitude of collaboration was essential.

Almost a year after the pandemic, it is possible to look back and identify the satisfaction for what has been achieved and for the lessons learnt facing adversity, recognizing the successes and mistakes experienced.

Regarding the experiences that were lived because of the pandemic, here are some stories from the collaborators. The Director of Educational Programs at FUNDAL, Adriana Segura, shares the following, "For me, the pandemic has been a challenge at the level of

organizing an entire team and transforming services. It has not only meant adapting the techniques, methodologies, processes, but it has also made changes in the mentality of many of the teachers and technicians. I have had to believe first that these new models work for the population with deafblindness and multiple disabilities, to be able to transmit it to the team. It has required, according to me, a double or triple job to convert each process from the service we provide to the way we report and what we report. This year 2021, with more experience, I have observed that the team is more organized and safer to provide services, which has improved the response of parents."

On the part of the teaching team, in the words of Teresa Grijalva, the experience for her has consisted of the following, "That day-to-day challenge to find a way to reach each person from their individuality has helped us to force ourselves with courage and integrity to break our own barriers down, when from one day to the next teaching had to be planned and organized through virtuality, how to make the sensory come through a screen? How to cross that barrier that distanced us? And how can we send the warmth of our treatment? It required studying, doing some research, creating, imagining and above all capturing, that is how after several attempts of trial and error, we succeeded. Listening to their teacher, seeing her so close, receiving detailed instructions, it is too much work, but we managed to contagious the family so they could enjoy it as well as we did as teachers. Although we continue to learn, strive, and stay up late, we have managed to reach every home and every heart, thereby achieving to be a link on the bridge to inclusion".

Project Pixan-Mexico and Model Programs

Introduction

Your track record and the fruits of your labor are often the best engines when it comes to moving forward with a new project. Perkins International's global leadership in education and the work we have done in Latin America for more than thirty years have become a solid foundation for our new Project Pixan in Mexico.

Pixan is an ancient Mayan word that describes the power that gives life to every human being, regardless of his or her ability. By 2030, Perkins, in collaboration with the Mexican State Secretaries of Education, educators and parents, plans to increase access to quality education for children with deafblindness, multiple disabilities and visual impairments (DB/MD/VI).

In Mexico, the public education system provides for children with disabilities to learn in two arrangements depending on their learning needs: via inclusion in regular school classrooms, or via access to specialized teachers in a Special Education School (SES). Project Pixan started with 3 schools: SES Tecoh in the state of Yucatan, SES 13 in Morelos and SES 7 in Aguascalientes. By 2030, we will have improved conditions in 31 public schools, reaching at least 2,500 children. As the quality of education improves and children thrive, we expect enrollment and retention will increase. In this way, children who are out of school today will be learning by 2030.



MARÍA A. VÁZQUEZ

PERKINS INTERNATIONAL, RESEARCHER, ARGENTINA
MARY.VAZQUEZ@PERKINS.ORG



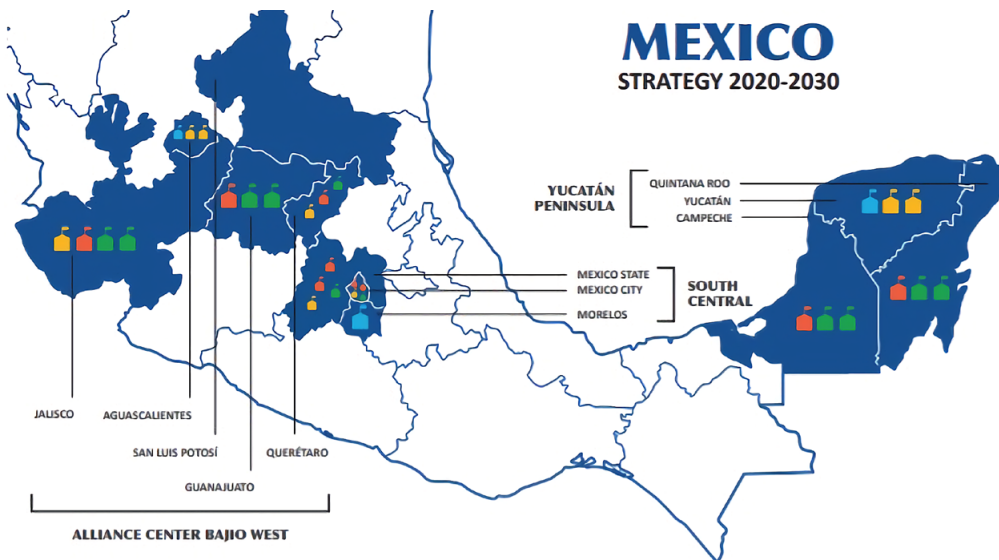
GLORIA RODRÍGUEZ-GIL

PERKINS INTERNATIONAL, DIRECTOR LATIN AMERICA AND THE CARIBBEAN, USA
GLORIA.RODRIGUEZ@PERKINS.ORG



MARTA ELENA RAMÍREZ

PERKINS INTERNATIONAL, MEXICO REPRESENTATIVE, MEXICO
MARTAELENA.RAMIREZ@PERKINS.ORG



KEY	
	PHASE 1: 2019-2021 MODEL ACCESSIBLE EDUCATION Total number of CAMs = 3
	PHASE 2: 2022-2024 SCALE AT STATE LEVEL Total number of CAMs = +8
	PHASE 3: 2025-2027 REGIONAL GROWTH Total number of CAMs = +9
	PHASE 4: 2028-2030 REGIONAL CONSOLIDATION Total number of CAMs = +11

Project Pixan 10-year strategy

EXCHANGE OF EXPERIENCE

Plan of Action

Two basic principles shaped our plan:

- participation and collaboration
- students and family as the center of all decision-making processes

Guided by these principles, schools are selected based on 6 criteria designed to gauge the motivation and resources at the school, community, and state government levels.

One Example: SES Tecoh

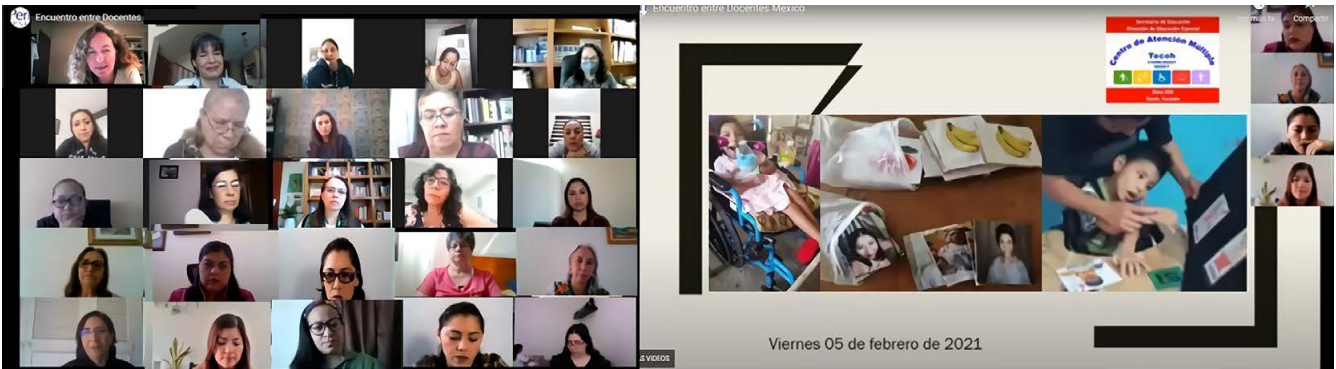


Alison with her mother demonstrating school materials produced by the school in time of pandemic and designed especially for the child.

Once the schools are selected, Perkins has focused in strengthening schools through training to all participants involved in the educational process of children/youth with DB/MD/VI, and supporting the design of strategies to increase impact and decision making for change by optimizing the use of resources. Involving local and national educational authorities is crucial to sustainable advances for learners, educators, parents, and the education system overall.

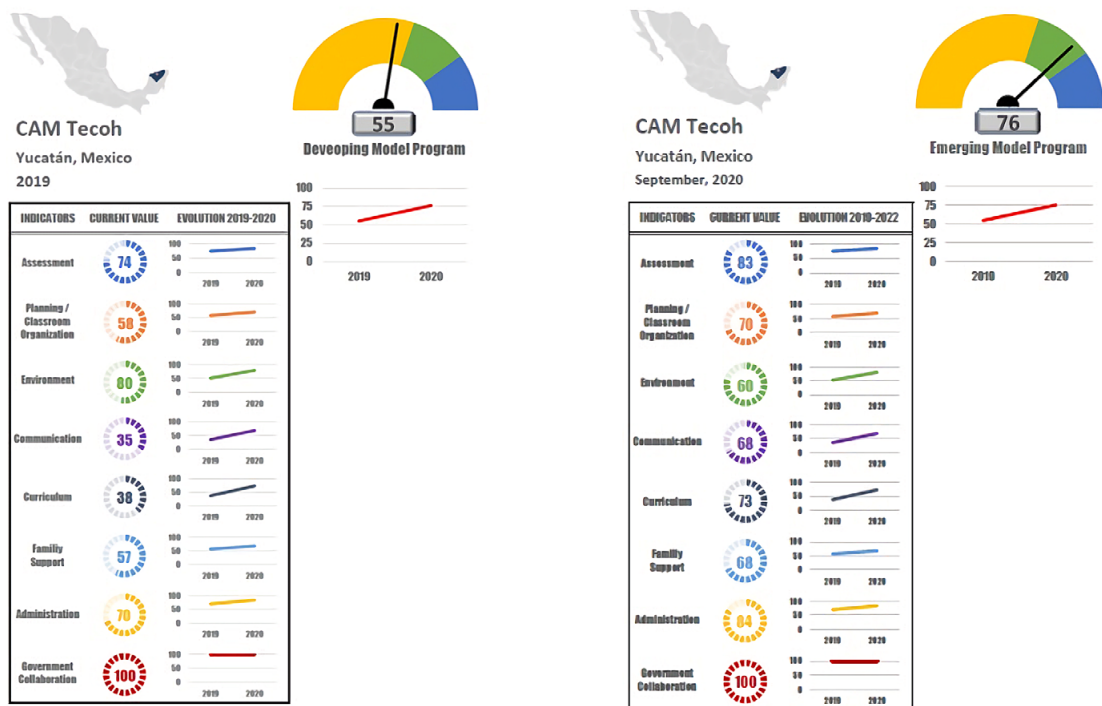
Each school has unique experiences in terms of pedagogy and social contribution in their communities. Our work with SES Tecoh began in September 2019. SES Tecoh is a rural school in a predominantly indigenous community with limited financial resources, but a great desire to improve the quality of learning and teaching. Perkins began by observing, evaluating, communicating, designing action plans, and training. Today, teachers share their stories of new educational strategies, adaptations, and knowledge exchanges. By incorporating Project Pixan strategies, the school teams are already seeing great progress in children.

Early evidence from both project data and reflections by the participants demonstrate enhanced leadership and commitment in addition to improved classroom practices. This progress has been achieved despite COVID limitations on in-person trainings and school closures. Indeed, in some cases, virtual gatherings broke down geographical barriers, enabling schools from different states to share best practices.



Regional meeting Mexico SES from Project Pixan, February 2021.

Link to the meeting: <https://youtu.be/aEW6zGmHvzo>



7 schematics prepared by Monitoring-Evaluation and Learning Team-Perkins International. Perkins Quality Indicators taken in September 2019 and September 2020 from Model Program in Development (Stage I) to Emerging Model Program (Stage 2).

The Road Ahead

During this time of work, Perkins has supported schools to respond to the needs of their students with DB/MD/VI by encouraging the development of innovative, flexible practices. This, in turn, brings community respect to the diversity of challenges faced by the school. Project Pixan has also fostered the participation of the Secretary of Public Education, which stands out as invaluable.

Their political support made us capable of reaching more families and teachers.

Many more children are still waiting to benefit from Project Pixan. Our approach of collaborative work and the commitment of all the participants are the seed for change that the children need.

Deafblindness in Rwanda



TERESA QUAIL

DeafReach, a UK registered charity, founded in 1971 has a long history of supporting deaf and deafblind children, and adults in the UK. In 2016, it added the support of overseas initiatives via partners in Rwanda, Uganda, Congo, and Burundi. DeafReach has an established association with Sense International, Uganda. Since 2019 DeafReach has been engaged in deafblind initiatives with partners in Congo and Burundi. Late 2019 presented an opportunity to conduct an action research project to understand deafblindness within the wider Rwanda disability context.

There is a dearth of information specific to deafblindness in Rwanda. This research sought to secure a broad picture of the prevalence of deafblindness in Rwanda, the circumstances of persons with deafblindness, policies towards them and services available. Then asking the question: If a mother brought a deafblind child to you seeking help, what would be the next step?

A DeafReach volunteer and an in-country partner volunteer conducted interviews with key personnel within as many relevant Government Offices, I/NGOs, Deaf Schools, Blind Schools, Voluntary Organisations, Federations and Civil Society Organisations as possible. The study highlighted that most personnel would not know what to do or what to advise, primarily because of the absence of knowledge of this disability, its prevalence and what assistance was available.

Examples of practice already in existence:

- the Rwanda Union of the Blind's (RUB) Masaka Centre has established training programmes in tactile sign language
- the Blind & Deafblind Association in Rusizi
- the combined partnership of the RUB with the SFDB
- A group of deafblind people are seeking formal registration of the Rwanda Organisation of Deafblind as an NGO via the Rwanda Governance Board

This approach provides a baseline analysis for the consideration of a practical response by DeafReach, its partners and friends in the development world. The global Covid-19 pandemic has limited DeafReach's progress with this specific project. However, as we move towards a post pandemic world, DeafReach hopes the project can, together with in-country partners, explore the creation of

an umbrella group of concerned and involved organisations and individuals to develop and make a coordinated whole-country response to the needs of deafblind people in Rwanda. In addition, DeafReach would like to explore a cross-border approach that includes involvement of the present emerging deafblind initiatives in both Congo and Burundi,

as three countries with such close historic ties and a common language.

Whilst we await the vaccinations, there is much to do in advance of the time when we can travel safely again. We are looking forward to learn from and engage with the deafblind international community at the first African-based conference in October.



Online Version of the Deafblindness Master Program in Groningen Creates New Opportunities for Sharing Knowledge

SASKIA DAMEN

UNIVERSITY OF
GRONINGEN &
ROYAL DUTCH
KENTALIS, THE
NETHERLANDS
S.DAMEN@RUG.NL

It is September 2020 when seven students of the 13th commencement of the international Deafblindness Master Program graduate from the University of Groningen in the Netherlands. The students come from New Zealand, Zambia, Germany, Japan, England, and the Netherlands and have followed a one year program in order to become Masters in Pedagogical Science with a specialization in Deafblindness. The participation of two of the students is made possible because of a scholarship. After the lapse of 13 years the Master still remains the only international academic program in deafblindness in the world. A part of the graduation of the students of the program is a presentation of their Master thesis on a symposium, for an audience of family, friends and colleagues. However, in 2020 the graduation ceremony didn't include real gathering. The COVID-19 pandemic demands another way of disseminating the results of the individual research projects in the form of an online webinar.



The students that started the Deafblindness Master Program in 2019 and the team of lecturers (except Dr. Paul Hart and Dr. Marja Cantell), well before the COVID-19 pandemic outbreak started.

On September 23, 2020 over 40 people from all over the world attend the graduation webinar by zoom and watch the presentations of the students. The presentations are diverse, reflect various interests of the students and their diverse backgrounds and circumstances. The first presentation is from Mariana Silva Algorta, who studied the creation of tactile signs for unfamiliar objects by a person with acquired deafblindness and a communication partner in New Zealand. Then Roy Reininga presents his study about well-being of people with congenital deafblindness in the Netherlands, from the perspective of their caregivers. The third presentation concerns a study of Vikram Choudhary about the benefits of age diversity in a peer-matching project in Germany, involving youth and adults with acquired deafblindness. The next presentation is held by Liliás Liston, who studied the building of peer relationships of a young man

with congenital deafblindness in England as a result of an intervention in which multiparty interactions in the tactile modality were stimulated. The presentation of Simate from Zambia is sadly not possible, because of a problem with the Internet. Therefore, his supervisor, Dr. Joe Gibson, explains that Simate is the first graduate of the Master Program with deafblindness, and that Simate analyzed meaningful communication between a girl with acquired deafblindness and her partners with deafness in Zambia. Then Emi Kamei from Japan presents her study of the communication of a student with congenital deafblindness in different educational settings. Finally, Ines Weber presents the results of her study in Germany that focused on the assessment of functional hearing of children with deafblindness. Ines dedicates her presentation to her colleague and friend Elisa Keesen who intended to follow the Master Program together with Ines, but

EXCHANGE OF EXPERIENCE

who was seriously ill and passed away in May 2020. The words of remembrance make a huge impression to everyone, among them former students of the Master and also students who have just started the program in September 2020.

Overall, the impression is that the online webinar is a good alternative for a physical symposium and that a huge benefit is that much more people are able to attend the event.

The students of 2020-2021 of the Deafblindness Master Program not only attended the online graduation webinar, but followed a fully online Master Program. Previous graduates of the Master Program used to come to Groningen in September and followed a four week program with full days of interactive lectures and assignment, and then went back to their countries to work on practice assignments and a research project with online supervision. In the 2020-2021 Master program, the practical and research part is similar to the one of the previous years, but due to the COVID-19 pandemic all the lectures are now held online. The lectures cover various topics related to deafblindness, such as assessment, social relations and identity, embodied and tactile cognition, interaction and communication, educator support, tactile sign language acquisition, and outdoor activities. In addition, students receive online lectures on research methods.

The international team of lecturers consists of Prof. Marleen Janssen from the Netherlands, Dr. Paul Hart from Scotland, Dr. Jude Nicholas, and Dr. Joe Gibson from Norway, Prof. Beppie van den Bogaerde, Dr. Marja Cantell, and Dr. Saskia Damen from the Netherlands. They use various didactic methods to make their online lectures interesting and interactive. Before entering the online classroom for example, the students are asked to watch a video clip in which the topic of the lecture is introduced and to make a short assignment. During each 3-hour lecture the assignment is discussed and students analyze video-clips, participate

in group discussions or prepare a presentation in break-out rooms. The online lectures are all being recorded and made available on an online student platform.

The experiences with the full online edition of the Deafblindness Master Program so far are mostly positive. Similarly to the previous year, most of the students already have a professional background in deafblindness or in a related field. They work as teachers, speech therapists, consultants, and caregivers for people with congenital or acquired deafblindness. Similarly to the previous years, the group of students is small, which creates opportunities to interact during the online lectures, share experiences and discuss the situation in the various countries. The lecturers experienced that the students were very engaged during the online lectures and are positive about the quality of their assignments. The students reported that they found the lecturers very interesting and that they have given them sufficient basis for deciding on their topic for the research project they are going to carry out in their own countries. However, the students also experienced the online lectures as intense ones and would have liked to have more time to prepare for the lectures.

The experiences of the 2020-2021 Master Program are now being used in the development of the program for the coming academic year. Because of the pandemic still being present, the team of lecturers again schedules a fully online program that starts in September 2021, but now with more time for students to prepare for each lecture. We hope that online version of the program will allow people, who won't be able to come to the Netherlands, for example because of their family situation or the distance between their country and the Netherlands, to follow the program. The deadline for admission is June 1 for all citizens. You can find more information on the program and scholarships following the links. Information on [the program](#) and [scholarships](#) can also be obtained by mailing to Saskia Damen, Curriculum Coordinator, at s.damen@rug.nl

Acquired Deafblindness Network (ADBN)

PETER SIMCOCK

peter.simcock@bcu.ac.uk

Adapted Physical Activity Network (APA)

MADS KOPPERHOLDT

mads.kopperholdt@rn.dk

CHARGE network

ANDREA WANKA

aw@andrea-wanka.de

Communication Network

MARLEEN JANSSEN

h.j.m.janssen@rug.nl

Creative Arts Network

EMILY WALTERS

Emily.Walters@ableaustralia.org.au

European Deafblind Network (EDbN)

RICARD LOPEZ

rlopez@sordoceguera.com

Ibero Latin America Network

XIMENA SERPA

ximena.serpa@gmail.com

Network of the Americas

MARIANNE RIGGIO

marianne.riggio@perkins.org

Outdoor Network

JOE GIBSON

deafblindoutdoors@gmail.com

Research Network

WALTER WITTICH

walter.wittich@umontreal.ca

Rubella Network

EDWIN OSUNDWA

edwin@senseint-ea.org

Technology network

MIJKJE WORM

mworm@bartimeus.nl

THOMAS RAGNARSSON

thomas.ragnarsson@nkcdb.se

DICK LUNENBORG

dlunenborg@bartimeus.nl

Usher Network

EMMA BOSWELL

Emma.Boswell@sense.org.uk

Youth Network

SIMON ALLISON

simon.allison@sense.org.uk



Being and becoming a member of Dbl

Throughout this brand-new digital Dbl Review you will surely notice: Deafblind International is THE point of connection in deafblindness worldwide.

This is our passion and this is also our vision. To connect more and more and more. And to increase the impact we have for people with deafblindness and their families. Which means for example growing exchange and learning from each other, identifying and promoting best practices, stimulating research in the field or advocating for international awareness and recognition of deafblindness as a unique and distinct disability.

For all of that and more we need YOU as a member. Being or becoming a member: Please help us growing our impact and becoming indeed worldwide THE point of connection.

Being an individual member of Dbl means

- being a part of THE network in deafblindness and in making a difference for people with deafblindness, their families, professionals, researchers and service organizations worldwide
- belonging to the international “Dbl family” and being in touch with members from all parts of the world
- being very much invited to join one of Dbl’s very active thematic networks
- being informed first-hand about news and developments in the field and before anyone else about upcoming possibilities to exchange and learn from each other as in one of Dbl’s conferences
- being able to publish in Dbl’s digital magazine “Dbl Review”
- having member discounts on Dbl’s upcoming merchandise

Being a corporate member of Dbl means means in addition to that

- cooperating with other specialized organizations on an international level for awareness and recognition of deafblindness as a unique and distinct disability, for inclusion, quality services, the needed specialized competence of the professionals, focused research and further improvements in assistive technology
- learning from and with other specialized organizations for your own
- having a chance to be directly involved in Dbl’s management and development as an elected member of the Board and/or of one of its committees
- presenting your organization during Dbl conferences in a booth provided free of charge

Dbl is all about connecting, **individual membership** is therefore **free of charge**.

Corporate members are **the foundation** for the work of Dbl, **also with their financial membership contribution**. That is their pride and that is why they play the key role in Dbl’s direction and management.

If you want to join us as a new member, just go to <https://www.deafblindinternational.org/about-us/become-a-member/> Anyway, being or becoming a member, we are enthusiastic about your power. Together we will boost Dbl’s impact for sure.

Mirko Baúr, Strategic Vice-President Dbl, Chair ComCom



Deafblind
International Dbl

DbI Communication Ambassador: Call for Action



DbI's newly formed Communication Committee (DbI ComCom) is reaching out your help!

We expect an Ambassador to take DbI's communication to the next level by leveraging your knowledge and expertise in this area. As the old saying goes, it takes a village.

We assume that an Ambassador has well established communications with local, regional and maybe national media, an inspiring website and/or an involving social media presence. We believe that these resources could help us to spread the word about deafblindness, quality services and DbI all over the world.

What are the responsibilities of a Communication Ambassador:

1. Assist DbI in ensuring that its social media posts are reposted on your organization pages within a short period of time (1-5 business days).
2. Assist DbI by ensuring access to your media network and sharing DbI press releases and communication with your media network within a short period of time (1-5 business days).
3. Assist DbI by having the key contact keep his/her ears to the ground to assist in sourcing regional news and information that could be shared with DbI membership and can be posted on DbI pages.
4. DbI would be grateful to have the key contact act as an ambassador and connector within their geographic area.

Organizations serving as DbI Communication Ambassadors will receive the official DbI Communication Ambassador Logo to be used freely in all of their communication. You will have your finger on the pulse of DbI's communication and be fully informed about worldwide developments in our field. Your organization will have a presence in the upcoming short film about DbI's Communication Committee ComCom. In addition, twice a year you will be invited to join an online meeting with ComCom to discuss the collaboration and the further development of DbI's communication.

Help us to make a difference for people with deafblindness worldwide and join us as a DbI Communication Ambassador! We are looking forward to your answer.

Please reach out directly to Roxanna Spruyt Rocks about your interest at r.spruytrocks@deafblindontario.com.