

DbI REVIEW

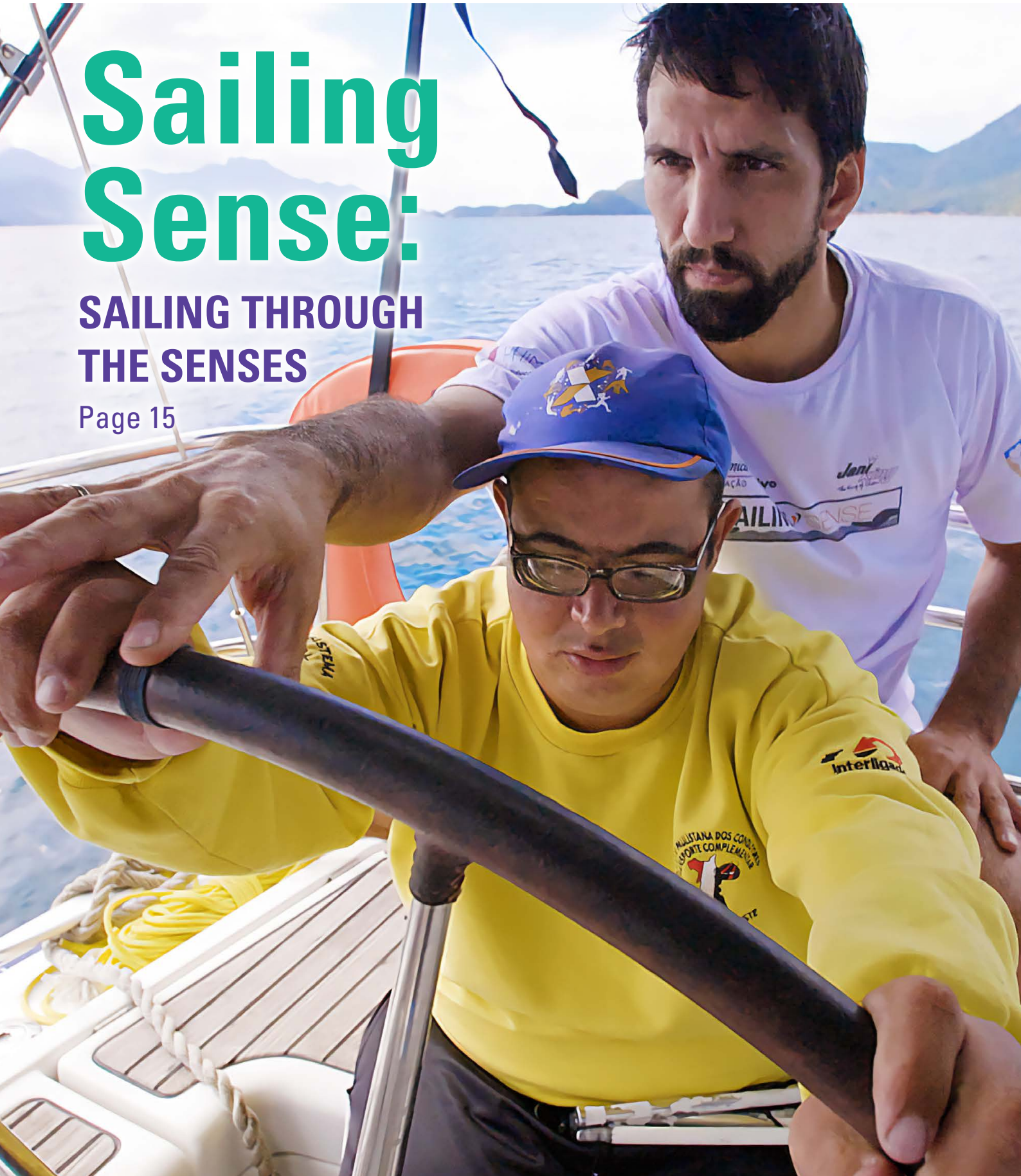
THE MAGAZINE
OF DEAFBLIND
INTERNATIONAL



Sailing Sense:

SAILING THROUGH THE SENSES

Page 15





Together Towards a Positive Future of Dbl and Its Mission!

Focus on a desired future helps in many crises. Looking at the positive future strengthens in the present and carries beyond in a maelstrom of energy. In the ongoing pandemic we can certainly all need that.

Dbl's strategy of course is about the future. All the more fantastic is the great progress we have made in all four of our strategic domains:

- Connecting through proactive internal and external communication
- Connecting through collaborations with the relevant international organizations
- Connecting through stimulating research and learning from each other
- Connecting through enhancing our culture of diversity and inclusion

You will certainly have noticed our new style of proactive communication. The new website for example. The much increased activity on our social media channels. The new network with Dbl Communication Ambassadors all over the world. All of that has become possible with the new group approach and the great collaboration between the Communication Committee ComCom, ManCom, the secretariat and active members. So it is connecting that leads to connecting through proactive communication. That is work, it is passion and also a lot of fun. Just watch ComCom's video: <https://www.youtube.com/watch?v=-VB-igkh5Ls>

Connecting is key for all other strategic domains as well. Collaborations with the relevant international organizations means reaching out and exchanging. Means participating actively. Means taking up ideas and inspiring new ones. That is definitely happening, inside of Dbl and beyond. One example of that is "Include Me" – an open source publication for families, caregivers,

community workers, educators, and friends who support and encourage children with multiple disabilities and vision impairment or deafblindness to participate in home, community and educational activities. Have a look at this great joint venture with ICEVI, CBM, Perkins International and the Indian Blind People's Association here: <https://icevi.org/include-me-mdvi-deafblindness-publication/>

Working on it we have indeed learned from each other, just as we have in Dbl's very 1st Webinar Series during Deafblind Awareness Week this past June. The series around the theme "Living with Deafblindness in a New Reality" were indeed a wonderful success in connecting around the globe – in spite of and focusing on COVID-19 at the same time. Without the passion of the grassroots team involved, especially of the hosts, it would not have been possible. If you missed it, you can find the videos of each webinar day on our website: <https://www.deafblindinternational.org/webinars/>

Not recent history yet but very well on the way are Dbl's African Researchers' Initiative (ARI) and Dbl's very 1st African Conference. There is now:

- A well running ARI with a great coordinator, a wonderful research advisory committee and 10 new research projects in Africa that will be presented at the conference
- A very capable conference organization with 1 planning committee and 5 sub-committees for logistics, content, publicity, fundraising and accessibility
- A connection with the World Federation of the Deafblind WFDB and the International Disability Alliance IDA to coordinate with the next Helen Keller World Conference
- A direct involvement of the team of Dbl's Young Researchers' Conference
- A venue in Nairobi, Kenya, a hopeful date with October 6 to 8 2021, and soon a logo

So we can indeed look at great progress towards a positive future. All of that and much more is the result of exchanging and collaborating, of standing together and co-creating what we want to be: Dbl - THE Point of Connection in Deafblindness Worldwide.

Let's go on doing that – together, now more than ever!

Mirko Baur, Strategic Vice President Dbl, Chair ComCom



Deafblind
International Dbl

IN MEMORIAM - ELISA KEESEN

➔ 3

NEWS

News from the Network Coordinator

➔ 6

A New Chapter for the Acquired Deafblindness Network (ADBN)

➔ 7

Technology Network

➔ 10

Network of the Americas Update

➔ 11

Research Network Update

➔ 12

Communication Network

➔ 14

Sailing Sense: Sailing through the Senses

➔ 15

ANNOUNCEMENTS

Yarn Bombing for Deafblind Awareness: June 2021

➔ 18

Call for Exchange of Information and Best Practice Examples

➔ 20

ARTICLES

Being a “Cognition Partner”: Supporting a Person with Deafblindness as a Subject

➔ 21

Growing up with Usher Syndrome

➔ 25

Teaching Others to Implement van Dijk’s Approach to Child-Guided Assessment

➔ 30

Service Gaps, Prevalence and Severity Specific Estimates of Deafblindness in Canada: A Report

➔ 34

INTERVIEWS

Janinne a University Student Who Was Born Deafblind

➔ 40

Rehabilitation Has Given me New Opportunities

➔ 45

Interview with Alexander Suvorov, a Participant of the Zagorsk Experiment

➔ 49

EXCHANGE OF EXPERIENCE

Seize the Moment and Reinvent our Lives

➔ 55

■ CONTENTS

Mission during Coronavirus Situation: "Put Something Similar Instead"

→ 60

How Innovation is Bridging the Educational Gap between the Living Room and the Classroom in Tanzania

→ 62

Online Diagnostic Sessions for Families of Deafblind Children

→ 66

International Collaboration on Video Interaction Guidance

→ 72

Connection and Learning in the Time of Covid-19 – A Time to Remember for the Ages

→ 74

Support to Everyone

→ 77

Sparkling Circus Artists at Bartiméus

→ 80

TECHNOLOGIES

Regional Information Accessible on Live TV Programs for Deafblind People

→ 85

Independent Dialogue between People with Hearing Impairment, Including Deafblind and People without Health Limitations. *Charly* Makes It a Reality

→ 92

NETWORKS AND NETWORK LEADERS

→ 95

In Memoriam – Elisa Keesen

Nur wer einen Schritt geht, dehnt seinen Lebensraum um diesen Schritt aus.

We mourn the loss of our colleague and friend Elisa Keesen, who passed away on May 16th, 2020, aged 31. Since 2016, Elisa worked as a special educational needs teacher at the counselling service for children and adolescents with deafblindness at the *stiftung st. frankziskus heiligenbronn*, Germany. She significantly

defined and accompanied many developmental paths of young people with deafblindness; besides, Elisa sustainably influenced and enriched the research in the field of deafblind-pedagogics in the German-speaking countries. Elisa's death has left a void, and, yet traces that will continue to inspire ourselves and our work.

COUNSELLING
SERVICE FOR
CHILDREN AND
ADOLESCENTS
WITH
DEAFBLINDNESS,
STIFTUNG ST.
FRANZISKUS
HEILIGENBRONN,
HEILIGENBRONN-
SCHRAMBERG,
GERMANY

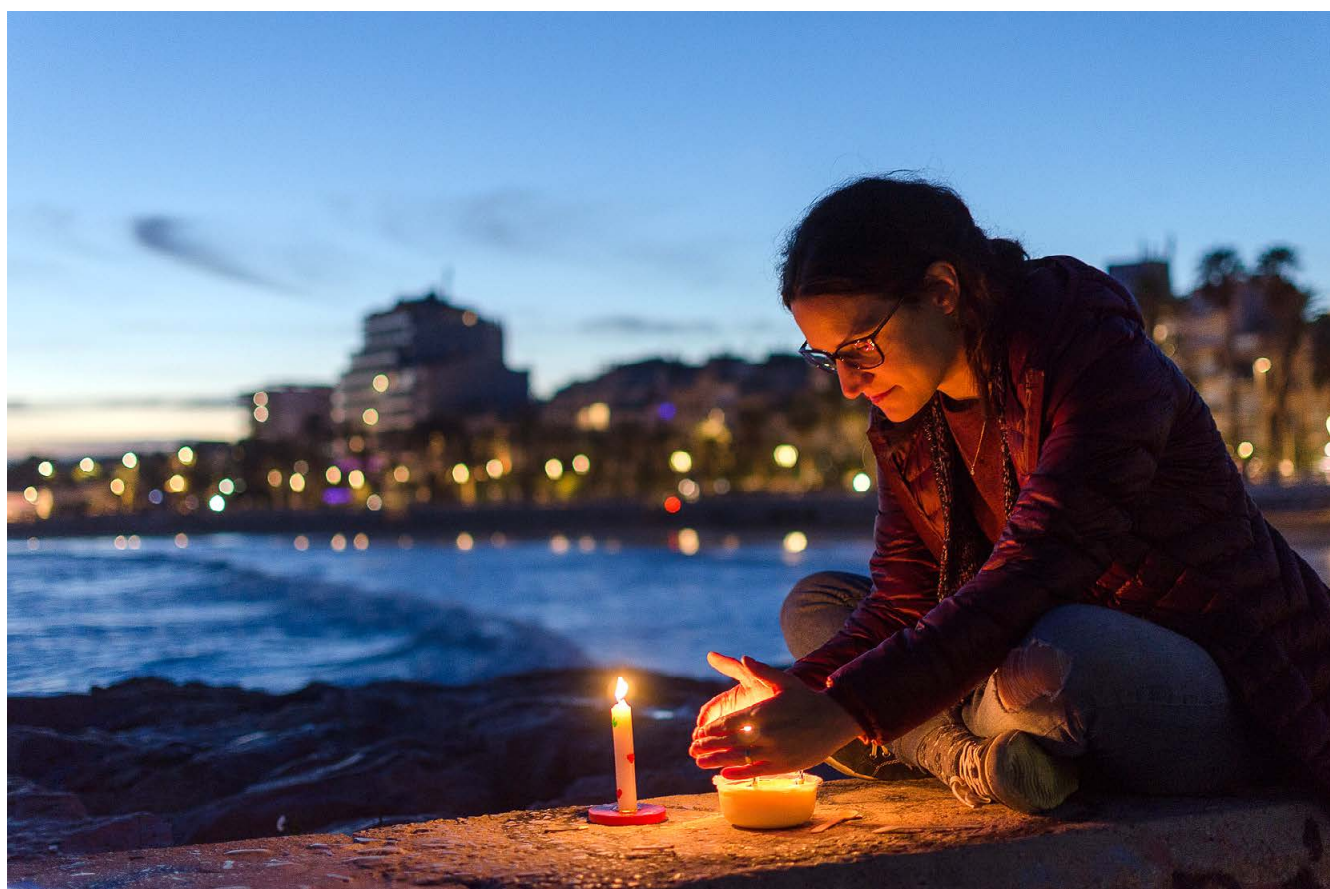


IN MEMORIAM

Elisa Keesen was born on November 1, 1988, in Augsburg, Germany. At the University of Education Heidelberg (Germany), she studied special needs education for the blind and the hearing impaired. After the first State Examination, she worked as a research assistant in the research project *Soziale Teilhabe und Fördersituation von Kindern und Jugendlichen mit Hörsehbehinderung/Taubblindheit* [Social Participation and Promotion of children and adolescents with Deafblindness] with Prof. Dr Markus Lang and Prof. Dr Klaus Sarimski. This period of research inspired Elisa to write a book on the construction of the world of people with congenital deafblindness. The publication explores the theory of the experience and development of action motivation in unique conditions. Moreover, the book focuses on basic psychological needs in subjective living spaces.

In 2016, Elisa faced the shocking and life-changing diagnosis of cancer. Nonetheless, she

continued to work exceptionally hard and highly motivated in the counselling service. Elisa's work was characterized by intelligent questions, analytical acumen and reflectiveness, an empathetic listening attitude, and the unwavering confidence in the potential of the children entrusted to her care. Her overall objective was to support children and adolescents with deafblindness to shape their developmental and educational pathways in the most meaningful way possible, and to commit herself to this with sympathetic emphasis. In December 2019, Elisa was awarded the *Young Professional Leadership Award* of the world association *Deafblind International*. Although the symptoms of her illness increasingly drained from her energy, Elisa was involved in numerous other projects in the field of deafblindness. It is hard to think, which significant contributions and deeds Elisa could and would have achieved, if she had had more time.



“Nur wer einen Schritt geht, dehnt seinen Lebensraum um diesen Schritt aus“ [Only by taking a step, one expands one’s living space by that step]. This is a quotation from her book *Angeborene Taubblindheit und die Konstruktion der Welt* [Congenital Deafblindness and the Construction of the World]. This statement illustrates how important it is to enrich our own lives with experience and knowledge. Elisa has taken these steps with great strength and clarity, with infectious enthusiasm and with an enormous exemplary commitment to children and adolescents with deafblindness.

We will miss Elisa and her sincerity and strength, her wisdom and humanity, her courage and determination, her broad horizon, and the wealth of ideas dearly. The deep sense of purpose that she has found and lived in her work with people with deafblindness will always accompany and motivate us.

Beratungsstelle für Kinder und Jugendliche mit Taubblindheit/ Hörsehbehinderung, stiftung st. franziskus heiligenbronn.



News from the Network Coordinator



TREES VAN NUNEN

DBI NETWORK
COORDINATOR

T.VANNUNEN@KENTALIS.NL

In this strange period in which Covid-19 asks so much of us, I am glad that we are able to keep in touch with each other through other channels. We meet more online and social media is more important than ever. In addition, we also discover other forces within ourselves, and we become more creative to deal with a changing world.

Of course, there were also disappointments: a number of activities organized by various networks could not take place and were postponed to 2021. But there were also bright spots: Dbi organized a series of webinars around the theme *Living with Deafblindness in a New Reality* together with the Research Network. Given the large number of participants and interested parties, we can conclude that we need each other even more. To share knowledge and to keep in touch with each other.

The ZOOM meetings with the network leaders continued as usual last year. It is very motivating to meet each other in this way.

There was a switch between network leaders, to mention that of the Ibero Latin America Network: Vula Ikonomidis passed the baton to Ximena Serpa. From this place I want to thank Vula very much for all the work she has done for this

network and I wish Ximena the best of luck in her role as network leader.

I am also very happy that the Acquired Deafblindness network (ADBN) has made a new start. Peter Simcock is the new network leader and he introduces himself in an article in this Dbi Review.

Thanks to the increased number of Dbi members, the number of members of the various networks is also growing.

Finally, I would like to end by welcoming a new Dbi network: the network on Technology. Elsewhere in this Dbi Review they introduce themselves.

I am proud of all the new developments within Dbi and in particular of the network leaders and their members who continue to make an effort to find and keep the connection with each other, especially in this new reality!

A New Chapter for the Acquired Deafblindness Network (ADBN)

The global pandemic, which has undoubtedly had a disproportionate impact on people with deafblindness, means that 2020 is a year we will not forget. Responding to the crisis, the European Deafblind Union (EDbU), the African Federation of the Deafblind (AFDB), the Latin American Federation of the Deafblind (FLASC) and the World Federation of the Deafblind (WFDB) developed inclusive policies, which were recommended to global organizations, individual states and governments, to ensure that the deafblind population was not overlooked at this time. Such international co-operation is key to the work of Deafblind International, as it brings together individuals and organizations across the globe in order to develop best practice in the deafblind field. I was therefore delighted to be invited to become the new chair of the Acquired Deafblindness Network (ADBN), and would like to take this opportunity to introduce myself.

How Meeting a Deafblind Person Determined My Career

My involvement in the deafblind field began in 1997, while working in the North West of England. I had taken the opportunity to take British Sign Language (BSL) classes at the local Adult Education College. During one of these classes, a representative from a local organization for visually impaired people met with us to request volunteers for the deafblind social group that she facilitated. I was intrigued and duly volunteered. The following week, for the first time in my life, I met a deafblind person. As I sat next to her, she felt my presence and extended out

her hand to receive tactual communication. With my rudimentary deafblind communication skills, we muddled through a game of bingo and engaged in conversation. This meeting determined the course of my career: although social work has been 'curiously inactive in the field [of deafblindness]' (Luey 1994:213), and there are few social work practitioners who specialize in sensory impairment, I went on to complete further academic and professional qualifications and became a specialist social worker for deafblind people.



PETER SIMCOCK

BIRMINGHAM
CITY UNIVERSITY,
DEPARTMENT OF
SOCIAL WORK,
BIRMINGHAM. UK

[PETER.SIMCOCK@
BCU.AC.UK](mailto:PETER.SIMCOCK@BCU.AC.UK)

Having spent ten years in social work practice, I left in 2010, and entered social work education; but my interest in social work with deafblind people has remained. Earlier this year I completed my doctoral research, which explored the experience of vulnerability from the perspectives of older adults

The Acquired Deafblindness Network

Though the provenance of campaigning organizations of and for deafblind people is often found in shared concern about the needs of congenitally deafblind children, the field of deafblindness has expanded. Organizations and the research community are now active in seeking to better understand and meet the needs of other members of the deafblind population, including those with acquired dual sensory loss. As the Chair of the Scientific Committee for the 16th Deafblind Intentional World Conference in Romania, Tony Best, noted, 'we are now becoming very clear about the needs created by deafblindness, and that many of these needs are experiences *whenever deafblindness occurs*'.

The distinction between congenital and acquired deafblindness is long-standing in research, policy and practice. Some have

Come Join Us

So, are you a person with acquired deafblindness, because of conditions associated with old age, or someone who became deafblind earlier in your life? Or are you a practitioner working with people with acquired deafblindness? Or maybe a researcher working or interested in the acquired deafblindness field? Maybe all three? Then please do join the Network. As a social worker by profession, I believe the development of our

ageing with deafblindness. I am especially interested in the experiences and needs of older deafblind people, particularly those ageing with dual sensory loss, and social work practice with deafblind people, including safeguarding and adult protection work.

argued that this distinction is overly simplistic and artificial, and my own research highlights that the ageing with deafblindness population, which includes people across this divide, specifically highlight its inadequacy. Nonetheless, acquired deafblindness has its own challenges, distinct from those associated with congenital deafblindness, and I am excited to work with people across the world, through ADBN, to share knowledge, experience and ideas to enhance our understanding, develop best practice and promote quality of service.

Under the leadership of the previous chair, Liz Duncan, ADBN became one of the largest networks recognized by Deafblind International, and I am very fortunate that Liz has agreed to continue to work with me, as we relaunch the Network this year.

knowledge base needs not only theoretical and research knowledge, but also that from lived experience and practice. We therefore welcome anyone with an interest in acquired deafblindness to join. We are also keen to hear your ideas about what you want out of the Network, so will forward a survey to all members soon. This could be webinars, events at conferences, or the sharing of contacts, but do tell us your own thoughts.

To become a member, simply contact me, and I'll be in touch:

PETER SIMCOCK

**Address:**

SCT173 Seacole Building
City South Campus
Westbourne Road
Birmingham
B15 3TN
UK

Twitter:

[@peterjsimcock](https://twitter.com/peterjsimcock)

Profile:

<https://www.bcu.ac.uk/education-and-social-work/about-us/our-staff/peter-simcock>

Email:

Peter.simcock@bcu.ac.uk

Telephone:

+44 (0)121 300 4281

Technology Network

MIJKJE WORM

[MWORM@
BARTIMEUS.NL](mailto:MWORM@BARTIMEUS.NL)

**THOMAS
RAGNARSSON**

DICK LUNENBORG

DBI TECHNOLOGY
NETWORK
LEADERS

We hear you think... A technology network? Yes, this is a new network within the DBI. In the spring of 2020, we applied for a technology network, since this DBI network didn't yet exist while technology is essential in our modern society. We, a group of Swedish and Dutch professionals, have been collaborating since approximately two years now. Together, we have done a range of activities to link technology to the needs of people with deafblindness. Perhaps you've attended Eric van Heuvelen's workshop at the Aalborg conference in 2018, where he presented the smart doorbell. Also, we have creatively applied the *Heartbeat* (a device which tells a person with deafblindness how far away the social partner is) in different circumstances. Both Swedish and Dutch students have done various studies on the intersection of haptics and technology. We participate in the SUITCEYES-project. And recently, a review article on assistive technology for people with deafblindness has been accepted for publication in *Frontiers of Education*.

However, we couldn't possibly be the only ones who are pioneering in this field! Therefore, this report is also an appeal: we are looking for new members from various countries. Which experiences do you have regarding technology for people with deafblindness? And which applications have been successful for you/ persons with deafblindness in your network?

We believe it is important to share experiences, so that all of us can inspire and learn from each other. Our focus is on the broad field of technology that is applicable for people with deafblindness, both acquired and congenital. We aim to find technology that encourages self-determination, communication, independence and entertainment. Activities refer to:

- Making existing and new technology in a wide range of branches, including ICT and audiology, accessible for people with deafblindness
- Collecting needs and ideas (related to this topic) from people with deafblindness. Finding technical solutions, either by adjustment of existing applications or by developing new technology
- Promote scientific research on haptic perception and haptic technology
- Share information about existing devices and applications in relation to persons with deafblindness and their involved professionals

We welcome new members! Would you like to join the network and share your activities, experiences and/or ideas? Do you want to keep in touch with the activities of our network? Or do you have any questions? Please get in touch and/or sign up on: mworm@bartimeus.nl

Network of the Americas Update

DbI Network of the Americas was established in 2018 when the deaf-blind community came together in Hyannis for the first DbI Network of the Americas conference. At this conference we heard so clearly how important it is for us to come together whenever we can and in the meantime, to stay connected. This has become the mission of our network. We want to be a place where we can share our successes, challenges and practices toward creating a barrier-free life to people with deafblindness.

We have convened a small leadership group for our network to plan activities that will provide our members across the United States, Latin America and Canada with an opportunity to learn from one another in a meaningful way. As we adapt to life during the pandemic, we have challenged ourselves to do what we can to

support families of children with deafblindness as they strive to provide learning opportunities for their children while balancing the demands of family life.

We are honored that Texas School for the Blind and Visually impaired (TSBVI) has enthusiastically become one of the lead organizations in the network and will tie their highly successful Deafblind Symposium as a Network of the Americas activity. The theme of this virtual conference is *Navigating the New World: Teachers of the Deafblind in Texas*. The dates are March 4–6, 2021. This will be a great opportunity for presenters and attendees from the network regions to participate and build relationships with one another. For more information please go to [TSBVI Symposium](#).

If you would like to join the network, kindly complete a membership form [DBI Network of the Americas Registration](#).

MARIANNE RIGGIO

NETWORK CHAIR

MARIANNE.RIGGIO@PERKINS.ORG



Deafblind International
Network of the Americas

Research Network Update

WALTER WITTICH

CHAIR OF DBI
RESEARCH
NETWORK

WALTER.WITTICH@UMONTREAL.CA

SASKIA DAMEN

DEPUTY CHAIR
OF DBI RESEARCH
NETWORK

S.DAMEN@RUG.NL

The Dbi Research Network is well into its 6th year of existence, and we continue to grow and expand. As of September 2020, we now have 140 members on our e-mail contact list.

Saskia Damen and **Flemming Ask Larsen** continue the maintenance of the Deafblind International Research Network – Facebook Group (<https://www.facebook.com/groups/158743377516989>), currently at 942 members and growing. Come look us up and join in the conversation! **Christine Lehane** continues to maintain of our Deafblind International Research Network LinkedIn group (<https://www.linkedin.com/groups/8339092/>), currently with 92 members.

The Action Research Working Group, led by **Susan Bruce** continues to promote collaborative opportunities (<http://research.deafblindinternational.org/collaborative-opportunities/>), and you can learn more about her efforts on our Research Network web page. Additional initiatives are always welcome, so please get in touch with any of the members of the Dbi Research Network, in case you have an idea you would like to share.

The 1st Dbi webinar was held on ZOOM from 22-26 June 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. Under the leadership of Deafblind International, the organizing committee was composed of:

- Frank Kat, President of Deafblind International (Dbi), at Sint Lucas, Netherlands;
- Mirko Baur, Vice-President of Dbi, at Tanne, Switzerland;
- Jude Nicholas, at Statped & Haukeland University Hospital, Bergen, Norway;
- Saskia Damen, Vice-Chair of the Dbi Research Network, at the University of Groningen, Netherlands;
- Michelle Borton, at Sensity, Canada, and
- Walter Wittich, Chair of the Dbi Research Network and host for the webinar, at the University of Montreal, Canada.

Wittich and Damen also operated as the scientific committee. The creation of the webinar was motivated by the cancellation of the World Blindness Summit in Madrid, Spain. The call for proposals resulted in 30 submissions from 12 countries across 5 continents, including Australia, India, the UK, the Republic of Ireland, Finland, the Netherlands, Norway, Sweden, Mexico, Brazil, the USA and Canada. The 26 selected live presentations each lasted 45 min, in order to allow the live international sign language interpreters to take 15 min breaks between presentations. In case you missed it, the recordings for 25 of these presentations are available on the

webinar tab of the conference web page of the Deafblind International website (<https://www.deafblindinternational.org/webinars/>).

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

- Prof. Dr. Walter Wittich, Canada (Chair) <http://www.opto.umontreal.ca/wittichlab/en/index.html>
- Dr. Saskia Damen, Netherlands (deputy) <https://www.rug.nl/staff/s.damen/?lang=en>
- Prof. Dr. Marleen Janssen, Netherlands (core-member) <https://www.rug.nl/>

[about-ug/latest-news/press-information/scientists-in-focus/mjanssen?lang=en](https://www.rug.nl/about-ug/latest-news/press-information/scientists-in-focus/mjanssen?lang=en)

- Dr. Meredith Prain, Australia (core-member) <https://meredithprain.com.au/>
- Dr. Alana Roy, Australia (core-member) <http://thesignsoflife.com.au/>

Please feel free to contact any one of us if you have any ideas for us, or other requests for research-specific information, we look forward to hearing from you, and please feel free to check out the networking opportunities on our web page <http://research.deafblindinternational.org/> and contact us with your interests and thoughts.

Communication Network

**MARLEEN
JANSSEN**

COMMUNICATION
NETWORK LEADER

[H.J.M.JANSSEN@
RUG.NL](mailto:H.J.M.JANSSEN@RUG.NL)

Our organization team, existing of Meredith Prain from Australia, Helle Buelund from Denmark and me, is in the middle of reorganization of our network and website page. In the next issue we will report more extensively about our past, current and future activities. Our current activities involve besides the reorganization of our network and website editing the Dbl Review book on Communication Overview of 40 years. Our future activities are focused on organizing a webinar about the basic principles of developing communication. In the smaller network connecting to our Communication Network, the graduation of new master students at the University of Groningen is being prepared besides an interesting alumni event about assessment of cognition in persons with congenital deafblindness. More information about these Master-study events you can ask Saskia Damen S.Damen@rug.nl

Furthermore several members of the Dbl Communication Network and Dbl Research Network are involved and very active in a current activity on the writing and editing of a Special Issue for Frontiers in Educational Psychology, entitled: Development, wellbeing, and

Lifelong Learning in Individuals with a Dual Sensory Loss, of which already 10 articles are accepted and published, from which three articles are focused on communication. In the next issue of Dbl Review I will report more details, when the Special Issue will be finished.

Another activity, where more members of the Communication Network are involved, in is the African Research Initiative. About the event connected to ARI you will read undoubtedly more in this and in the next issues.

And last but not least, on August 27, Kitty Bloeming-Wolbrink from Royal Dutch Visio graduated from the University of Groningen on her PhD thesis *Interaction, Communication and Stress in Adults with Congenital Deafblindness and an Intellectual Disability*. Three articles have been already published. You can find more information on the website:

[https://www.rug.nl/about-ug/
latest-news/events/promoties/
promoties-2020?hfid=100955](https://www.rug.nl/about-ug/latest-news/events/promoties/promoties-2020?hfid=100955).

For more information, or if you have questions about this network, contact Marleen Janssen, on behalf of the Dbl Communication Network team: h.j.m.janssen@rug.nl

Sailing Sense: Sailing through the Senses

The documentary *Sailing Sense: Sailing through the Senses* was launched on June 27, 2020, online on YouTube. The documentary *Sailing Sense: Sailing through the Senses*, by Umanoid Studio, presents some deafblind persons and their life experiences.

Mário Carmo, Carlos Jorge Rodrigues, and Nelson Cordeiro were the three deafblind men invited to sail from Paraty to Ilha Grande, on the coast of Rio de

Janeiro (Brazil). During the documentary, Cláudia Sofia, a deafblind woman who is married to Carlos Jorge, was also interviewed to talk about her life experiences.

ANDREY CINTRA GOMES MARCONDES

SENSE INSTITUT,
SÃO PAULO,
BRAZIL, ARCHITECT
OF UNIVERSITY
OF CAMPINAS,
CAMPINAS, SÃO
PAULO, BRAZIL
ANDCGMARCONDES@GMAIL.COM

MIGUEL MARTIN OLIO

SENSE INSTITUT,
SÃO PAULO,
BRAZIL
MIGUELMARTINOLIO@GMAIL.COM

IRIS FERNANDES POFFO

SENSE INSTITUT,
SÃO PAULO,
BRAZIL
IRISP@UOL.COM.BR



Carlos Jorge Rodrigues, a deafblind man



Mario Carmo, a deafblind man and Miguel Olio, an instructor



Nelson Cordeiro, a deafblind man

The video has subtitles in Portuguese and audio description. Check the documentary at:

<https://www.youtube.com/watch?v=iw1x-few7bY>

Soon after the release of the documentary, Carlos Jorge and Cláudia Sofia were interviewed in a live event on YouTube. The deafblind couple had a guide-interpreter using Tadoma to communicate with Cláudia Sofia and Tactile Libras (Brazilian Sign Language) to communicate with Carlos Jorge. They talked about the experience of participating in the documentary. The interview was recorded and it can be watched on YouTube at:

<https://www.youtube.com/watch?v=ZXOjywE4Bbl>

Yarn Bombing for Deafblind Awareness: June 2021



**ROXANNA
SPRUYT-ROCKS**

DBI COMCOM -
COMMUNICATION
AMBASSADOR
LEAD; CHIEF
EXECUTIVE
OFFICER,
DEAFBLIND
ONTARIO
SERVICES,
ONTARIO, CANADA

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

Communication Ambassadors

Deafblind International (Dbi) is the point of connection in deafblindness worldwide. Connecting, of course, means communicating. Dbi's newly formed Communication Committee, also referred to as 'ComCom', encompasses Communication Ambassadors from six continents across the globe. Ambassadors

have well established relationships with local, regional, and potentially national media, along with an inspiring website and social media presence. They bring forward their communications expertise and keep a finger on the pulse of Dbi's communications efforts and worldwide developments in the field.



Communication Ambassadors List:

Africa: Mary Maragia (Kilimani Integrated Primary School, Kenya), Victor Locoro (Kyambogo University, Uganda)

Asia: Sampada Shevde (Perkins India), Namita Jacob & Hassan Currimbhoy (Chetana, India)

Australia: Jane O'Keefe (Able Australia), Matthew Wittorf & Melissa Evans (Senses Australia), Meredith Prain (DeafBlind Australia), Emily Walters (Deafblind Information Australia), Frances Gentle (ICEVI-Network > worldwide)

Europe: Richard Kramer (Sense, UK and international), Elisabeth Schuetz (Sense, UK and international), Eugenio Romero Rey (ONCE, Spain), Trees van Nunen Schrauwen (Kentalis, the Netherlands and international), Mirko Baur (Tanne, Switzerland and "German Network"), Deirdre J. Leech (Anne Sullivan Centre, Ireland), Darija Udovicic Mahmuljin

(Perkins, Europe and Eurasia), Dmitry Polikanov (Con-nections, Russia), Julien Mast (CRESAM, France)

North America: Susan Manahan (DeafBlind Ontario Services, Canada), Chris Woodfill (Helen Keller Centre, USA), Samantha Gaspar (Sensity, Canada)

South America: Ricardo Zevallos (Sense International, Peru), Carmen Lucía Guerrero (Guatemala), Isabel Galindez & Raul Gutierrez (ASOMAS, Mexico), Carolyn Sanchez (CIDEVI, Chile), Graciela Ferioli (Argentina), Yvette Gallegos Barro (Mexico)

Yarn Bombing 2021: An Awareness Initiative

Collaboratively, Dbl ComCom and Communication Ambassadors will spread the word about deafblindness, quality services, and Dbl across the globe. In June 2020, Dbl ComCom teased an announcement during the month-long deafblind awareness social media campaign. On June 27, we shared that our awareness initiative for 2021 will be yarn bombing.

A phenomenon sometimes known as 'knitfiti', yarn bombing is a type of graffiti or street art that displays colorful yarn that is knit, crochet, or wrapped around an object(s) in a public space. It is thought to have originated in the United States in 2005.

Global yarn bombing for our 2021 awareness campaign is an exciting, fun, and creative way to engage members of the deafblind community in a largescale tactile art project. 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 for appropriate services for people who are deafblind around the world.

By coming together in June (and preparing in the months leading up to it), to yarn bomb objects in as many cities and countries as possible, we strive to foster connections and unite a community with individuals,

service and advocacy groups in the field, Dbl members and partners, and the wider global public.

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, colorful yarn and get crafty! More details are coming soon, visit deafblindinternational.org



Call for Exchange of Information and Best Practice Examples

MELISSA GLOMB

**VERENA
TAMBORINI**

JANA MARTIN

CAROLIN FESSER

NIKOLAUSPFLEGE -
FOUNDATION FOR
BLIND AND VISUALLY
IMPAIRED PERSONS,
STUTTGART,
GERMANY

[WEGE-IN-
DEN-BERUF@
NIKOLAUSPFLEGE.DE](mailto:WEGE-IN-DEN-BERUF@NIKOLAUSPFLEGE.DE)

WEGE IN DEN BERUF
WEGE IN DEN BERUF



Gefördert durch die

**Aktion
MENSCH**
Stiftung

Through the financial support of *Aktion Mensch* Foundation, a new project (named *Wege in den Beruf*) was launched in Germany in June 2020 with the goal of developing appropriate vocational rehabilitation services and vocational training programs for people with deafblindness.

Specialized vocational rehabilitation services empower people to manage their everyday personal and professional lives as independently as possible using assistive devices, tools specially designed for deafblind people, communication strategies (e.g. tactile sign language), and special orientation and working techniques. They enable people to resume their previous professional activities and/or to start a vocational training program or a new job. Vocational training programs offer the possibility to learn new professional/ vocational skills, communication strategies or even an apprenticeship in a new profession.

The project is a collaborative effort between *Nikolauspfl ege Stuttgart*, *Deutsches Taubblindenwerk gGmbH* in Hannover and *SFZ Förderzentrum gGmbH* in Chemnitz and Berlin, to provide relevant expertise and extensive resources.

Programs developed through this collaboration will be implemented in four cities (Stuttgart, Hannover, Chemnitz, and Berlin). Every person with deafblindness in Germany will be eligible to participate in these programs.

The new program, organized in modules, will be customized to the needs of each participant. It will provide an important basis for vocational and social (re)integration.

As there are currently no specific vocational rehabilitation services or vocational training programs for people with deafblindness in Germany, we want to ensure that new programs are of the highest quality. Therefore, we are looking to our international colleagues for best practice examples of vocational rehabilitation services and vocational training programs.

Do you work for an organization providing specific vocational training programs or vocational rehabilitation services for people with deafblindness? Alternatively, is your organization planning to develop similar types of programs?

If you are interested in exchanging information and experiences, or have further questions concerning our project and objectives, please feel free to contact our project manager, Melissa Glomb.

Contact: Melissa Glomb, wege-in-den-beruf@nikolauspfl ege.de

Being a “Cognition Partner”: Supporting a Person with Deafblindness as a Subject

The following is an elaboration of the notion of “partner perspectives” and the role of the communication partner as described by Nafstad and Rødbroe (2009, 2015), to suggest a parallel, but distinct partner role, that of the “cognition partner”. Cognition is here defined pragmatically in terms of the actions of thinking and exploring/learning, and as an embodied phenomenon. The role of cognition partner is described in terms of several key “attitudes” that promote a partner focus on the person with congenital deafblindness as a thinking and feeling, autonomous subject.

It is perhaps most practical for professional partners of people with congenital deafblindness (CDB) to view cognition as exploration and learning (the latter is most easily seen in the transferal of skills or knowledge developed in one situation, to new settings or situations). As communication partners for people with CDB, especially those with little or no cultural language, we take an approach in our interaction with them that involves attention to the embodied aspects of this interaction. We are also interested in the qualitative characteristics of the embodied contributions to this interaction that people with CDB may make.

Some of these may be:

- mimetic expressions
- imitating, or doing something “over again” in the sense of re-enactment of a previous action or event
- directing attention, including “pointing” and other bodily indications of attention- directing and intentionality of expression
- categorization activity: exploring the physical characteristics of the world, things, and other people. For example, by investigating structural aspects of movement-in-the-world that come to form the cognitive schematics¹ through which experience in the world can be organized



KIRSTEN COSTAIN

SENIOR ADVISER,
NATIONAL UNIT
FOR COMBINED
VISUAL AND
HEARING LOSS AND
DEAFBLINDNESS

KHCV12@GMAIL.COM

¹ Typical schematic pairs are, for example, “in” and “out”, “up” and “down”, “forward” and “back” (Johnson, 1987). Johnson (1987) describes how these schematics, meaningful (cognitive) patterns initially shaped from small, repetitive physical experiences and actions, are gradually generalized across experiences, and become more abstract over time. These abstract categorizing units are reflected in cultural linguistic expressions that refer to emotional and psychological experience; for example: “I feel very down today”, “he’s moving up in the world”, “She’s down and out”. This last expression involves two schematics: in – out as well as up – down.

Embodied cognition can be thought of as thinking with and through the body (including, but not restricted to, the brain), and through bodily experiences. These experiences function as the basis for meaning structures which become tools for thinking and for learning to think about further experiences with and in the world. In taking an embodied cognition approach we can say that there is no thought or thinking, and no communication, without the body.

By taking a subjectivity perspective in our encounters with the person with CDB (viewing the person with CDB as a subject), and by taking the time to (temporarily) move away from the intersubjective orientation of the communication partner, we can sometimes facilitate, observe and assess cognitive activity in a clearer way. To achieve this, we need to be aware of the expansion of our support or partner role from communication and social interaction partner to include a cognition partner role in affording access to context. To achieve this, the partner of the person with deafblindness needs to take the *YOU* perspective toward the person with CDB. Nafstad and Rødbroe (2015) describe three perspectives of the partner in terms of the *I* or first-person perspective, the *YOU* or second person perspective, and the *IT* or third person perspective. The *I* perspective is the perspective of the partner herself, sometimes projected on to the subjectivity of the person with CDB. There can be good reasons for taking this perspective in trying to identify what the person with CDB is feeling or interested in communicating, though it is also important to identify and own one's partner perspective by clearly indicating that it is a perspective on the thoughts and feelings of the person, rather than the thoughts and feelings themselves.

The *IT* perspective also has its place, but can very easily become dominant, and can lead to objectification of the person with CDB. This is the opposite of treating the person as a subject. The *IT* view is often signaled by use of the third person pronoun (he/she) as in, "He always does that when we go out"; "She doesn't like to use signs", "She never wants to join in when we have gym", "He loves loud music". This perspective is often voiced

in totalizing or black-and-white statements like these that become labels and stamps as though the person is an object to map out or a collection of tendencies and attributes to identify. As new partners, we need to acquire detailed information about the people we are partnering, such as learning their likes and dislikes, their personalities, how they tend to behave in different situations; this is all part of learning how to partner distinct individuals in the best possible way. However, if we remain in this *IT* mode too long or too often, we can very easily fall into a "business as usual" attitude in which we have great difficulty in seeing the new or emerging contributions and needs of the person as a developing individual. Instead of partners, we can quickly become "managers" of the fixed entity that is the objectified receiver of our care.

In the *YOU* perspective, on the other hand, the partner's focus is on the person with CDB as a subject. A subject is a *someone* who understands and thinks, who expects something from the environment, who is cognitively and emotionally present, and who has her or his own perspective. A subject feels something whereas an objectified individual merely reacts; a subject acts whereas an objectified person merely demonstrates behavior. The point is not that people with CDB don't also react and behave in certain ways, but rather that the reduction of their way of being in the world to these categories alone in the *IT* perspective closes off their personhood in ways we ourselves would find unacceptable if we were regarded in the same way (for example, do you merely react to the death of your father, or are you grieving his loss?).

All three perspectives are likely to be operating alongside one another in good quality partnering, and sometimes it is necessary to take a strong *IT* perspective in certain situations. For example, there is a lot of traffic on the normally quiet road and Sam's love of balancing on the edge of the sidewalk is not a good thing to indulge right now. In taking a *YOU* perspective we would need to anticipate Sam's actions (*IT*), inform him about the situation, and negotiate resuming balancing later on when we enter a quieter

street, rather than suddenly dragging him off the sidewalk edge. Then again, perhaps we are forced to drag him off the edge as a vehicle unexpectedly swings around to enter a driveway right in front of us (strong *IT*). Deciding before we go out the door together that current conditions will make it too dangerous for Sam to do his balancing act and preventing him from being able to choose to start in the first place by taking a different route (*I*) is also an option that is sometimes the best one in the situation. Partners must make dozens of such decisions and assessments all the time, and it is easy for certain *IT* and *I* tendencies to creep in and take over. This is because it is extremely challenging and uncomfortable not to know how things are going to go, to feel out of one's depth or thrown into a new situation in which one is suddenly a beginner instead of an expert.

Taking the *YOU* perspective towards the person with CDB can be thought of as maintaining a kind of "beginner's mind" about the person and about one's own practice. This beginner orientation allows the partner to be open to making discoveries about the person with CDB, to new developments and opportunities for communication and interaction with the person, as well as new ways of working as a partner. Taking this more dynamic perspective can be described in terms of (also) being a cognition partner, as the focus is on the person with CDB as an experiencing and learning, thinking subject who needs support in their exploration of the world. Being a good cognition partner can be helped by cultivation of certain "partner attitudes" that emphasize the *YOU* perspective. Here is a suggested list of such attitudes:

- *Wondering*: including taking what in therapy is called the "not-knowing position" (Anderson & Goolishian, 1992) as an active position; suspending one's own prior knowledge in choosing not to "know"
- *Listening*: being a listener as much as one is a speaker, thus supporting participation in dialogue and communicative agency; treating the person with CDB, regardless of formal linguistic ability, as

a contributor to as well as a recipient of, communication

- *Being expectant*: expecting something from the person with CDB as part of an active way of being with the person
- *Following* the person with CDB, following her initiative
- *Mirroring* the person's actions or initiatives by reflecting these back to the person with CDB in an attuned manner (not merely using "mirroring" as a technique).
- *Confirming*: for example, by speaking "out loud" (in a vocal and/or tactile manner) about what one as partner sees that the person with CDB has done, is engaged in or attempting to do; providing a supportive commentary rather than using a confirmatory gesture in a mechanical fashion.
- *Being addressed to* (also without directly addressing) the person with CDB
- *Allowing*: suspending intervention and allowing the person with CDB to act and express; making space for new things to occur through an attitude of allowing things to happen
- *Refraining* (in the moment) from doing, saying, or meaning something; as above, allowing for a space to enter between our perceiving and then acting on our perception; taking our time. This space can be very potent for both the partner and the person with CDB.
- *Being informative*: not necessarily only through language but through an orientation, also bodily, of providing the person with CDB the best access to context through information. The word *in-forma-tion* suggests meaningful gestalts or holistic units of meaning, not isolated facts, or directives. The partner takes this into account in maintaining an informative attitude.
- *Observing*: more than merely being observant; viewing the child as a subject in a fresh and inquisitive manner. Suspending our urge to categorize as we

do this (that is for later when we are not actively partnering but rather reflecting over our practice).

- *Being with* the person with CDB (in Norwegian, the phrase is “being together with”, and this is closer to the meaning I want to promote here). Accompanying the child in an engaged side-by-side manner.

Of course, all this is a very tall order, and not possible to sustain perfectly, or all the

time, and sometimes not at all. The extent to which we stretch toward these sorts of attitudes, however, will have a great deal to say about how well we are truly able to partner people with CDB. This role involves taking time to clear ourselves away a bit, to leave more space in the moment for the other person to appear for us as a person (as well as a person with CDB). The cognition partner attitudes may be useful in describing in practical terms ways we can reveal for ourselves and thus support the subjective autonomy of personhood of the person with CDB.

References

Anderson, H. & Goolishian, H. (1992). The client is the expert: a not-knowing approach to therapy. In K.J. Gergen and S. McNamee (Eds.), *Therapy as social construction*, Sage: London, Thousand Oaks, CA. pp. 25-39.

Johnson, M. (1987). *The body in the mind: the bodily basis of meaning, imagination, and reason*. Chicago: The University of Chicago Press.

Nafstad, A. V., & Rødbroe, I. B. (2015). *Communicative Relations*. Aalborg: Materialecenteret.

Growing up with Usher Syndrome

Acknowledgments

This work was a joint collaboration between CFD and Institut for Syn, Hørelse og Døvblindhed (ISHD). Bettina K. Pedersen, Karina H. Sejler and Eva J. Toldam carried out the seven interviews, and I am grateful for their support, which made this article possible. A preliminary literature review was done which indicated a need to

focus on young people with Usher syndrome and their risk and protection factors in their daily life. This pilot study was all about giving voice to children and young people with Usher and, hopefully, this knowledge will benefit both practitioners and children and their families in dealing with Usher syndrome.

Why Is It Crucial to Investigate the Lives of Young People with Usher?

Learning how to live and adapt to a life with deafblindness can be a challenge for people with Usher syndrome. Due to the progressive loss of sight and hearing, Usher requires multiple adaptations. The constant adaption to new conditions means that the world can be perceived as inhospitable, and people with deafblindness are largely in risk of isolation. Various studies¹ have shown that people with Usher are at risk of developing depression, anxiety and stress, and the existence of suicidal ideation for people with Usher indicates a great need of action towards this group. Though epidemiological and genetic studies have shed light on certain valuable aspects of Usher, research concerning the qualitative experience of living with Usher has unfortunately not been giving very much attention, and "...there is a need for more qualitative research to develop an in-depth

understanding of the needs and experiences of this population." (Jaiswal, Aldersey, Wittich, Mirza & Finlayson, 2018, p. 18). Qualitative studies have been focused primarily on adults with Usher, and no studies have been based solely upon the perspectives of children or young people with Usher. Early intervention by professionals could potentially prevent the inexpedient consequences of living with Usher. Thus, this study investigated how young people with Usher syndrome perceive everyday-life growing up with Usher syndrome. Using a phenomenological-inspired approach, we sought to explore and understand the young people's accounts of growing up with Usher, and how the syndrome affects their conditions of life. Identifying the experiences of these young people might render new insights for professionals' working with Usher.



**RASMUS
HOUGAARD
PEDERSEN**

PSYCHOLOGIST
AT INSTITUT FOR
SYN, HØRELSE OG
DØVBLINDHED,
AALBORG,
DENMARK

[RASMUS.
PEDERSEN@RN.DK](mailto:RASMUS.PEDERSEN@RN.DK)

¹ See e.g. Wahlqvist, C. Möller, K. Möller & Danermark (2013) and Wahlqvist, K. Möller, C. Möller & Danermark (2016)

Methods

Two educational consultants from ISHD and one development consultant CFD conducted seven interviews based on a semi-structured interview guide, which was inspired by the biopsychosocial model (Engel, 1980) and the bioecological model of human development (Bronfenbrenner, 1994). Six of the young people interviewed were female, the median age was 18 years, and the interviews had duration between 40 mins and 128 mins. With a special focus on the narratives of the young people, the interviewers were also curious to new perspectives, which could turn

out to be meaningful for the interviewees. The author transcribed and analyzed the interviews using elements from *Thematic Analysis* (Braun & Clarke, 2006) and *Qualitative Content Analysis* (Hsieh & Shannon, 2005). The data analytic approach involved the reading and re-reading of the transcriptions, the development of initial codes, the revision of the initial codes to more general codes across the interviews, and the formation of themes and subthemes reflecting the young people' accounts of growing up with Usher.

Perspectives on Growing up with Usher

The comprehensive analysis identified 10 themes, which prompted a perspective on growing up with Usher. An overview of the 10 themes is illustrated in Figure 1. Though

all themes provide a useful perspective, the following four themes give a sense of the results as a whole.

Figure 1. The themes and subthemes.

Themes	Subthemes
<i>The discovery of Usher</i>	
<i>The understanding of Usher</i>	The response to the syndrome Developing a different perspective on Usher
<i>Feeling of otherness</i>	
<i>Consequences of the dual sensory loss</i>	Physical implications on health Mental implications
<i>Getting an education and working with Usher</i>	Getting an education with Usher Working with Usher
<i>Relationships</i>	Family Friends
<i>Meeting other people with Usher or sensory loss</i>	
<i>Support</i>	The degree of support Being ready
<i>Usher management strategies</i>	
<i>The future with Usher</i>	

The Understanding of Usher

Central to the young people in this study was in which way they received the diagnosis and how they understand Usher. Four of the participants explicitly told about their difficulties in realizing that they got the diagnosis and which implications it might have. The background of this difficult process of realization was a denial of the consequences on their way of life. As one of the young people stated, "I could not be bothered to relate to my chronic illness anymore, [...] after all I've done fine till now, so what does it matter then." This denial of the syndrome can lead to reluctance to accept the offered help, and some of the participants became isolated and were angry with people in their environment. Another participant reported, "I didn't want to realize, that I've got some kind of problem. Thus, it was more a problem for me that I didn't want to accept the help the teachers and others offered me. At that time I felt, I don't have it [the syndrome], and I don't want to be perceived like someone."

As the syndrome and sensory loss progresses the participants expressed that they were not able to 'fake' the syndrome anymore. The challenges of living with Usher grow larger, hence the need for acknowledgement and acceptance of the syndrome increases, which make it possible to seek and acquire the appropriate support. The

Feeling of Otherness

The participants had a pervasive feeling of otherness or being different from their peers. They want to be treated as normal young people and didn't want to be perceived as a person with disabilities. One of the participants stated, "...I don't really like to get special treatment." This reluctance to be treated or be perceived differently from others has the consequence that they try to hide their disabilities by getting an education on the same terms as their peers or attempting to overcompensate. However, their efforts are often energy intensive and are likely to be a barrier when meeting other

young people reported that you need to "... trust the time..." focusing on the process of realization as specific to the individual. Though the young people might rationally acknowledge the need for accepting Usher and its implications on everyday life, they find it difficult to cope with emotionally, "Of course I can make sense of it rationally, but emotionally I wasn't ready at all..." However, the young people seem to express an ambivalence, in which they find the process of realization more difficult when one becomes older. There is a need to acquire support at the right time to alleviate and cope with the limitations of living with Usher in everyday life. Generally, they also stated that early detection of Usher seems to prompt a different and more integrated understanding of living with a progressive condition. Practitioners working with young people and children with Usher find themselves in this ambivalence of knowing that the implications of the sensory loss increase as the children grow up, hence they would need support and guidance from people around them. On the same time, practitioners have to be careful and respect the individual and their process of accepting a life with Usher syndrome. Pushing the child too hard to accept life with Usher and, on the contrary, not preparing or explaining the implications of Usher could both have psychosocial consequences.

people with Usher or other disabilities because it will be a reminder of their own disabilities. Therefore, the feeling of otherness might be a hindrance to accept their challenges and get the needed support. One of the young people expressed, "... you might as well say that we each are different in our own different way but that doesn't mean, that we're not able to do anything." The feeling of otherness might indicate a stigmatization towards people with disabilities, which is worth noticing in working with people who have Usher.

Getting an Education

All of the participants offered reflections and experiences on getting education with Usher. The most apparent problem in getting education is teachers' neglect of the young peoples' needs, and young peoples' accounts are a call for more awareness of Usher in their environment. Though the following participant attended a special school, the teachers weren't sure of her needs, "It was like they didn't really understand what I needed." In consequence of this lack of awareness, some of the young people felt excluded and

had experiences, where they were bullied or isolated. Transitions between different institutions and to higher educations do also pose a challenge to the young people with Usher. Adjusting to a new environment and interacting with new classmates are potentially very energy intensive like one of the participants expressed it, "...you were dozing off, when the teacher was talking. I was totally washed out." The environment needs to be aware of these transitions and their implications on concentration.

Support

Since all participants covered this theme, there is a variety of perspectives to follow. The support in the immediate environment is dependent on the understanding of participants' needs. Some of the participants feel that the support in especially educational institutions has been insufficient and very difficult to attain. Therefore, the participants rely upon different individuals such as deafblind consultants, contact persons and psychologists. One of the participants explains the invaluable support of the deafblind consultants to know how schools and education should adapt to the needs of persons with Usher to implement an environment for learning and development. Two of the participants had been in therapy, and it

is an aspect that might be highly underrated, "... I wonder why you can't get any psychological counselling, because there is so much assistive technology to receive, but I think that you just underestimate this aspect of therapy and conversation."

However, some of the participants stated, that they weren't ready to receive the support. They might feel exposed if the support is given before they are ready. The lengthy process of realizing that support is necessary to live with Usher syndrome can be expressed through following statement: "... some of the things that I fought with back then, I still fight with today in accepting that it is alright to get help."

Significant Aspects of the Interviews and Implications

Several themes focused on the difficult process of realizing the consequences of living with Usher syndrome. As a participant mentioned, it is like "losing something constantly", and this dynamic process of coping with dual sensory loss can be explained as the interplay between *avoiding the sensory loss* and *being confronted with the sensory loss*. The participants expressed this ambivalence in their daily lives growing up with Usher, and their accounts suggest that accepting and realizing the consequences of the syndrome is quite complex, reversible, and not something to get over. Practitioners need to be aware of this dynamic interplay when working with children and young people with Usher

syndrome. Moreover, the pervasive feeling of otherness described by the participants might be a testament of the stigmatization and alienation of people with deafblindness, and the feeling of being different from their peers could be important in understanding the risk at developing psychosocial health problems. The study offered an understanding of the conditions of life for young people with Usher syndrome, and how their perception of their syndrome and the immediate environment influenced the young people. Seven interviews with young people dealing with Usher syndrome give a variety of perspectives that could be pursued. The identified themes can be translated into practice,

and highlight, for instance, the need for early diagnostics, better introduction to the syndrome, an increased focus on support in education, and a desire for more individual psychological support adapting to a life

with deafblindness. Future studies can build on certain themes identified in this inquiry to further shed light on and support young people growing up with Usher syndrome.

References

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- Bronfenbrenner, U. (1994). Ecological models of human development. In *International Encyclopedia of Education* (2nd Ed., pp. 1643–1647). Oxford: Elsevier.
- Engel, G. L. (1980). The Clinical Application of the Biopsychosocial Model. *American Journal of Psychiatry*, 137(5), 535–544.
- Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277–1288. <https://doi.org/10.1177/1049732305276687>
- Jaiswal, A., Aldersey, H., Wittich, W., Mirza, M., & Finlayson, M. (2018) Participation experiences of people with deafblindness or dual sensory loss: A scoping review of global deafblind literature. *PLoS ONE*, 13(9): e0203772. <https://doi.org/10.1371/journal.pone.0203772>
- Wahlqvist, M., Möller, C., Möller, K., & Danermark, B. (2013). Physical and psychological health in persons with deafblindness that is due to Usher syndrome type II. *Journal of Visual Impairment and Blindness*, 107(3), 207–220. <https://doi.org/10.1177/0145482x1310700305>
- Wahlqvist, M., Möller, K., Möller, C., & Danermark, B. (2016). Physical and psychological health, social trust, and financial situation for persons with Usher syndrome type 1. *British Journal of Visual Impairment*, 34(1), 15–25. <https://doi.org/10.1177/0264619615610158>

Teaching Others to Implement van Dijk's Approach to Child-Guided Assessment

SUSAN BRUCE

SUSAN.BRUCE@BC.EDU

CATHY NELSON

HEATHER FRANCIS

This is the third in a series of articles about the assessment of children and youth who are deafblind, with an emphasis on those who are prelinguistic to early linguistic communicators. Children and adults who are deafblind are a highly heterogeneous group of learners whose strengths, learning characteristics, and needs cannot be fully identified through the sole use of formal assessment instruments or through completely static assessment procedures. They require us to engage in the process of discovering who they are as learners through a child-guided (as opposed to adult-directed) approach. Child-guided assessment falls within the category of dynamic assessment, a form of assessment, in which the assessment process changes in response to the learner's actions and may include brief periods of instruction followed by observation of the child's response to instruction. Unlike other assessment approaches, the child-guided assessment is constructed to discover answers to important questions such as how the child learns and how best to teach the child, rather than to assess narrow or isolated skills (Brown, 2014).

Around the world, many professionals have had the opportunity to observe Jan van Dijk demonstrate his approach to the child-guided assessment, which may also be applied with adults who are deafblind. Sadly, van Dijk passed away in 2018, so it is left

to experienced professionals to carry on his efforts to educate others to implement his approach. This article will provide basic information about van Dijk's approach to assessment and share one method for teaching others to implement his approach.

Orientation to van Dijk's Approach to Assessment

Nelson & Van Dijk (2001) encourage us to start the assessment process by gathering information from the parent(s) and others who know the child well. The actual assessment begins with putting the child at ease and establishing a positive interaction with the child. This may include the need to involve a person the child trusts, such as a parent or teacher. The child's interests and preferences are embedded into the assessment process for the purpose of discovering what the child knows and how the child learns. A routine is established with the child and the assessor adds a new sensory element to the routine. The assessor then observes for the child's habituation, which involves a change in the child's initial response as she becomes accustomed to the new element. Within their article about the van Dijk approach to assessment, Nelson, van Dijk, et al. (2002) present eight areas of focus for this assessment approach: (1) biobehavioral

state, (2) orienting response, (3) learning channels, (4) approach-withdrawal, (5) memory, (6) interactions, (7) communication, and (8) problem solving. Their article includes specific questions to pose related to each of these eight focus areas. These questions may be answered by directly interacting with the child or by observing others interact with the child, in the context of activities that are enjoyable for the child.

Although the van Dijk approach is fluid and individualized for each child, a study by Nelson, Janssen, et al. (2010) showed that practitioners in the field of deafblindness were able to implement the assessment with fidelity to quality indicators after a half-day training and self-guided exercises in the Nelson & van Dijk (2002) DVD. In addition, in all of the areas covered in the assessment, multiple examiners including practitioners in the study were able to reliably reach similar conclusions.

Applying van Dijk's Approach in Pre- and Inservice Educator Preparation

This activity is an effective method to prepare university students or in-service teachers to apply the van Dijk approach to assessment. They must learn to identify the child behaviors that van Dijk has asserted to

be of importance and they must also learn to identify and implement the assessment and instructional strategies he has recommended. Here is a practical procedure to support these goals.

Advance Preparation

Instructor's advance preparation includes selecting a DVD and specific video clips to be used during the activity-based instruction. One option would be to use the book of Nelson, van Dijk, Oster, & McDonnell (2009) with accompanying DVDs. A variety of van Dijk's DVDs have been produced in different languages, so you may select your favorite one. In my (the first author's) practice, I use the DVD by Nelson and van Dijk (2001). This particular DVD features an electronic folder for each child assessed. Inside each folder are video clips of van Dijk interacting with the child, and some of these video clips also include the parent. When preparing this activity for the first time, the instructor will

need to view each of the video clips and identify which clips best address each of the eight focus areas listed above (as they appeared in Nelson & van Dijk, 2002). For example, within the folder of videos of van Dijk working with Brian, video clips #4, 5, 6, and 7 were identified as providing especially good examples of memory, interactions, communication, and problem solving (which includes cause-effect relationships).

Students should prepare for the activity by reading Nelson et al. (2002). It is also helpful for them to view this video: *Child-Guided Assessment with Jan van Dijk*, located at <https://www.youtube.com/watch?v=KJA3PrOYdkA>.

Day of Activity

Step #1: Provide the university students or other participants with the list of the 8 focus areas and associated questions which appear on p. 99 of the Nelson, et al. article (2002).

Step #2: Preface the activity by defining terms and concepts that may not be familiar, such as biobehavioral state and habituation.

Step #3: Divide the class into three groups and provide them with a direction sheet, and then review the directions verbally. Here is one set of directions you may use:

Group #1 will watch videos of van Dijk's interaction with children to observe for biobehavioral states, orienting response, learning channels, and approach-withdraw.

Group #2 observes for memory, interactions, communication, and problem solving.

Group #3 observes for the 14 strategies that are part of van Dijk's approach. The strategies are stated below with questions that can be posed of the pre- or inservice teacher.

1. Make the child feel at ease (What did van Dijk do to make the child feel at ease?)
2. Determine child's behavioral states. (How did van Dijk elicit different behavioral states?)
3. Determine child's interests (How did van Dijk determine the child's interests?)
4. Follow child's interests (What examples did we see of van Dijk following the child's interests?)
5. Establish a routine (What routines were established?)
6. Use small increments of change (What examples did you see of van Dijk making small increments of change within the routine?)
7. Elicit a signal for continuation of activity. (How did van Dijk elicit these signals?)
8. Imitate the child and see if the child imitates you. (What examples of imitation

did van Dijk demonstrate? What examples of imitation were demonstrated by the child? What did he do to encourage imitation?)

9. Add one sensory modality at a time during the assessment (In what sequence did van Dijk introduce each sensory modality?)
10. Identify child's orientation response (How did the child orient to van Dijk and others? What did van Dijk do to draw child's attention?)
11. Provide opportunity for child to solve problems (What problem solving opportunities did van Dijk provide?)
12. Observe child's approach to learning (How did van Dijk learn more about child's approach to learning? What did he learn about child's approach to learning about objects or people?)
13. Provide opportunities for the child to show anticipation (What did van Dijk do to create opportunities for anticipation?)
14. Use child's preferred channels for stimulation and learning (Nelson, van Dijk, Oster, & McDonnell, 2009). (How did van Dijk create opportunities for the child to use different learning channels? How did he determine the child's preferred channel?)

Step #4: Show each video clip you have selected and then pause so that students can take a note about what they observed. Ask if they need to see the clip again. If you are showing only some of the video clips, show them in the sequence they appear on the DVD.

Step #5: After reviewing all of the selected video clips on a child, ask each group to report back, and also allow the other two groups to make additional comments. This supports each group to remain engaged.

Step #6: Change roles (by reassigning groups) so that each university student or inservice participant has an opportunity to think deeply about all 8 assessment focus

areas within the approach and to identify associated assessment strategies. The discussion should include identification of what

van Dijk did in the video clip and what was learned about the child (relevant to the eight focus areas).

Follow-up Activities

Once students are familiar with the basic concepts and procedures involved in the van Dijk approach to assessment, and they have successfully engaged in the guided activity, they will benefit from additional practice. The book written by Nelson et al., (2009) and Nelson & van Dijk's (2002) DVD are very suitable for an independent study. The DVD included in the 2009 book (slated to be a USB memory stick in the revised American Printing House for the Blind edition) contains two assessments. The first illustrates specific points made in the book and the other allows student to practice the assessment and check their answers against those of the authors. Assessment worksheets and parent interview questions are also included in the book.

Additional instruction is needed to show university students and others what to do with the results of an assessment using the van Dijk approach. The instructor may explain or

demonstrate how the results can be used to create a profile of assessment findings for one child. Students may also be asked to generate learning goals for the child based on the assessment findings. They may then be asked to apply their skills by assessing a child or a young adult. Novices in this approach may find it difficult to address all of the eight elements at once. It may be helpful to suggest that they interact with the child, focusing on implementing the recommended strategies. In addition, they can discover findings on perhaps two or three of the eight areas of focus (listed earlier) within a single interactive session. The other focus areas will be addressed in subsequent interactions with the same learner. It is too much to expect them to implement all of the strategies and observe for all eight of the focus areas until they have practiced these skills. This approach will encourage them to try van Dijk's approach and to build their confidence for future assessment efforts.

References

- Brown, D. (2014). What does "follow the child" mean? *Resources*. San Francisco: California Deaf-Blind Services.
- Nelson, C., Janssen, M., Oster, T., & Jayaraman, G. (2010). Reliability of the van Dijk assessment for children with deaf-blindness. *AER Journal*, 3(3) 71-80.
- Nelson, C., & van Dijk, J. (2001). *Principles of assessment for children with multiple sensory disabilities or deafblindness*. The Netherlands: Instituut Voor Doven.
- Nelson, C., van Dijk, J., McDonnell, A. P., & Thompson, K. (2002). A framework for understanding young children with severe multiple disabilities: The van Dijk approach to assessment. *Research & Practice for Persons with Severe Disabilities*, 27, 97-111.
- Nelson, C., & van Dijk, J. (2002) *Child-guided strategies for assessing children who are deaf-blind or have multiple disabilities (CD ROM)*. Louisville, KY: American Printing House for the Blind.
- Nelson, C., van Dijk, J., Oster, T., McDonnell, A. (2009). *Child-guided strategies: The van Dijk approach to assessment*. Louisville, KY: American Printing House for the Blind.

Service Gaps, Prevalence and Severity Specific Estimates of Deafblindness in Canada: A Report

ATUL JAISWAL

CIHR HEALTH SYSTEM POSTDOCTORAL FELLOW, SCHOOL OF OPTOMETRY, UNIVERSITY OF MONTREAL, MONTREAL, CANADA

ATUL.JAISWAL@UMONTREAL.CA

RENU MINHAS

KAREN MADHO

KAREN KEYES

ROXANNA SPRUYT-ROCKS

DEAFBLIND ONTARIO SERVICES, TORONTO, ONTARIO, CANADA

Acknowledgements

The authors would like to express sincere thanks to all the participants who shared their insights.

Background

DeafBlind Ontario Services (DBOS) is a not-for-profit organization that provides accessible residential and customized support services across the province of Ontario, Canada. DBOS released a position paper in January 2019, *A Canadian Perspective to the World Federation of the Deafblind (WFDB) report, At Risk of Exclusion from CRPD and SDG's implementation: Inequality and Persons with Deafblindness* to promote discussion and contribute to the development of improved national data collection on deafblindness (DBOS, 2019a). The WFDB report provided a global picture of realities faced by people with deafblindness and estimated prevalence of deafblindness as between 0.2% and 2% of the world's population (WFDB, 2018). The DBOS position paper highlighted the challenges faced by Canadians with deafblindness

and the need for appropriate professional supports – Intervenor Services. Based on another position paper *Open Your Eyes and Ears – To Estimates of Canadian Individuals with Deafblindness and Age-Related Dual Sensory Loss*, DBOS estimated the prevalence of deafblindness as 1% of the Canadian population, and this estimate was in alignment with the range reported in the WFDB's report (DBOS, 2018a & b). Though the WFDB report did not include population data from Canada, the two position papers echo the realities that individuals with deafblindness face. We realized the need to leverage the momentum and work together with individuals with deafblindness and related stakeholders in building awareness about the needs and rights of individuals with deafblindness in society.

Project Details

This article is based on the report of a project consultation

commissioned by DBOS from May 1, 2019 to July 30, 2019, to

inform the organizational advocacy strategy. It summarizes the key findings of the report on the prevalence of deafblindness in Canada and service gaps locally and nationally for a successful rights-based advocacy campaign (DBOS, 2019b). The report was prepared based on a preliminary analysis of the Canadian Survey on Disability (CSD) data 2017 from Statistics Canada and consultations with individuals with deafblindness and service providers in Canada. Thirty-five key stakeholders (individuals with deafblindness and service providers) identified by DBOS were emailed about the project, of which 20 stakeholders participated in the consultation.

Out of 20 stakeholders, six were persons with deafblindness and 14 were service providers from the following provinces: Ontario, British Columbia, Alberta, Manitoba, Quebec, and New Brunswick. The full report is available at <https://deafblindontario.com/about/publications/>

Here, we first present the preliminary analysis of CSD data 2017 on prevalence estimates of deafblindness and then underscore the deafblind-specific service gaps nationally from interview consultations. Finally, we conclude by providing recommendations and implications for policy and practice.

A Statistical Profile - Prevalence and Severity of Deafblindness in Canada

The 2017 CSD is a national survey of Canadians aged 15 and over whose everyday activities are limited because of a health-related problem (Statistics Canada, 2018). DBOS obtained customized data on deafblindness (based on the reported seeing and hearing

disabilities) from the CSD 2017 survey (released November 2018).

The prevalence estimates obtained from the CSD 2017 suggest that around 1.67% of the Canadian population above 15 years of age has deafblindness (Table 1).

Table 1. Estimates based on the Canadian Survey on Disability 2017 – Canada

Age Group	Total population of Canada	Persons with seeing and hearing disabilities	Estimated percent of individuals with deafblindness in Canada
15 years and over	28,008,860	466,420	1.67*
25 to 64 years	18,636,250	212,050	1.14
65 to 74 years	3,241,250	105,620	3.26
75 years and older	1,975,920	137,580	6.96

*These estimates were calculated as follows: $1.67 = (466,420/28,008,860) \times 100$

The estimates suggest that the prevalence of deafblindness increases with increasing age, both, confirming the strong relationship between aging and concurrent hearing and vision loss. These findings align with those of the WFDB's report (2018) and support findings provided by DBOS in their previous position papers of 2018 and 2019 (DBOS, 2018a; 2019a).

With respect to severity-specific estimates*, data from CSD 2017 suggest that in Canada, of those who have deafblindness, around 10% have a severe form of deafblindness (both hearing and vision loss are more severe), while 63.5% have less severe deafblindness (both hearing and vision loss are less severe) (See Table 2).

Table 2. Severity specific prevalence rates of deafblindness in Canada

	Severity specific prevalence rates	Total	
		Number	%
Canada	Total - Severity class (Seeing and Hearing)	466,420	100
	Seeing is less severe, and hearing is less severe	296,090	63.5
	Seeing is more severe, and hearing is less severe	62,470	13.4
	Seeing is less severe, and hearing is more severe	62,330	13.4
	Seeing is more severe, and hearing is more severe	45,530	9.8

*Severity scores in CSD 2017 were developed using the Disability Screening Questions (DSQ), and severity classes were established for each disability type based on the following severity scores: less severe (a score less than 0.5) and more severe (a score of 0.5 or more). Please see CSD 2017 Concepts and Methods guide, in particular pages 65-67 for further information.

Note: Ontario data table is available on request from r.minhas@deafblindontario.com

Service Gaps Locally and Nationally

Across Canada, provincial governments and territories are responsible for the delivery of support services for individuals with disabilities. For individuals with deafblindness, these supports and services are Intervenor Services¹. Although Canada has ratified the UN Convention on Rights of Persons with Disabilities in 2010, no right-based approach to inclusive disability services and supports at federal, provincial and territorial governments is provided. Services are provided on a discretionary, rather than universal basis to people who meet specific eligibility criteria – often based on a medical model of disability². Currently, there are no accountability measures in place to hold provinces and territories responsible for the consistent and

equitable delivery of Intervenor Services across Canada. In the absence of a clearly articulated set of measures across Canada, individuals with deafblindness continue to experience limited access to employment opportunities, reduced social connections with their peers and challenges to remain active and independent.

Stakeholders (individuals with deafblindness and service providers) identified many service gaps in Canada, which included **interprovincial variation in services; limited funding for intervenor services, limited intervenor hours and choice; lack of equitable access to assistive technology and range of rehabilitation services**. They highlighted the lack

1 <http://www.deafblindnetworkontario.com/ishrs/glossary-of-terms/>

2 Submission of Canadian Civil Society Organizations to the Committee on the Rights of Persons with Disabilities – July 26, 2019

of funding, organizational resources, and strategic planning for senior-specific services for age-related dual sensory loss (DSL) in Canada. The major service gaps for communication support included access to and availability of intervenors and limited intervenor training. Limited access and affordability of assistive devices were highlighted as significant barriers for those with deafblindness across provincial jurisdictions. Another gap highlighted by individuals with deafblindness was limited training opportunities for them to learn how to use assistive technology effectively in the light of the fact that technology programs change rapidly, and people with deafblindness often experience challenges to learn new programs to adapt to changing technology. They reported that often a lack of training leads to discontinuation in the use of the device.

Regarding **access to healthcare**, stakeholders reported challenges in communication with healthcare providers, difficulty in reading the information on medication packages and prescriptions, providing consent

for medical procedures, and navigating the healthcare system. While individuals with deafblindness expressed service gaps in terms of emergency intervenor support services that are required in the hospital or at home, service providers highlighted a lack of life-long support services for those with deafblindness and additional complex medical conditions. Human resource shortages were indicated by most participants as a critical concern, primarily due to the limited training available for intervenors.

Viable **employment opportunities** for adults with deafblindness are another considerable gap highlighted by the service providers. They reported that more employment supports are needed to train and help them acquire skills for relevant jobs. Also, there are very limited opportunities for people with deafblindness to travel outside of their home province with intervenor supports, and this is another service gap that needs to be addressed to improve their outdoor mobility and independence.

Recommendations and Implications for Policy and Practice

Stakeholders highlighted the need for advocacy with the government for support to develop **“Equitable services and support from coast to coast”/equitable access to services and supports from coast to coast**. Robust preschool services, deafblind-specific early intervention programs, and transition support from school to adulthood across the country are essential to address the needs of Canadians with deafblindness. They vehemently echoed the need for recognition of deafblindness as a distinct disability, education and awareness of this unique disability, and provision of deafblind-specific services such as Intervenor Services. They recommended advocacy for “senior-specific services for age-related DSL” in Canada, equitable access to assistive devices and related training, individual choice for communication support, standardized training of health care

providers, and education of caregivers/parents and individuals with deafblindness to advocate for their rights. They highlighted the need for more research in the Canadian context that could inform the development of services and assistive devices to improve communication, access to information, and overall functioning. These findings reiterate the gaps and suggestions for policy and practice as highlighted in the previous work by some researchers in the field of deafblindness where they asserted the need for recognition, deafblind specific resources and communication support, and adequate participation opportunities for individuals with deafblindness (Dammeyer, 2015; Jaiswal, Aldersey, Wittich, Mirza, & Finlayson, 2018; Wittich, Jarry, Groulx, Southall, & Gagné, 2016).

Limitations

Potential limitations to the analysis of CSD 2017 datasets include: exclusion of the 0-14 age group, the institutionalized population, people living in collective dwellings, such as Canadian Armed Forces bases, and the population living on First Nation reserves, and hence do not provide the complete extent of deafblindness in Canada and does not

quantify the number of people with different type of deafblindness (i.e. congenital, acquired and age-related DSL). Hence, though these estimates are based on the population census, actual numbers within specific age groups may be different and more than these suggested estimates.

Conclusion

To improve services for people with deafblindness, it is imperative to collect reliable and comparable data based on a consistent definition and accurate measures for deafblindness. A strong advocacy opportunity will be to address recognition of deafblindness as a distinct disability and its inclusion in disabilities list as well as production of data products on a regular basis to highlight the needs of individuals with deafblindness by the CSD group. Consultations with individuals with deafblindness and service providers, underscore some of the major service gaps locally and nationally in Intervenor Services and the need for a deeper understanding about deafblindness. This will lead to answering research questions that are

relevant to service providers/consumers and decision makers when improving policy and making more informed government decision. The authors endeavor to share the findings with various stakeholders to advocate for the service needs and promote programs and equitable access to improve outcomes for quality of life of all groups of Canadians with deafblindness – congenital, acquired and/or those who have age-related DSL (before the aging baby boomers begin to lose their hearing and sight). Coordinated and collaborative action is imperative at all levels of government, service providers and consumer to be proactively prepared to manage the service demands of Canadians with deafblindness.

References:

Dammeyer, J. (2015). Deafblindness and dual sensory loss research: Current status and future directions. *World Journal of Otorhinolaryngology*. 5(2), 37-40. <http://dx.doi.org/10.5319/>

DeafBlind Ontario Services. (2018a). *Open Your Eyes and Ears – To Estimates of Canadians with Deafblindness and Age-Related Dual Sensory Loss*. Retrieved from <https://deafblindontario.com/wp-content/uploads/2019/03/Open-your-eyes-and-ears-report-September-2018-kpm-edits-Feb-8-2019.pdf>

DeafBlind Ontario Services. (2018b). Deafblind Ontario Services position paper - Recognize Deafblindness as a Single Disability: Open Your Eyes and Ears, **DBI Review**, pg 43.

DeafBlind Ontario Services. (2019a). *A Canadian Perspective to the World Federation of the Deafblind report, At Risk of Exclusion from CRPD and SDG's implementation: Inequality and Persons with Deafblindness*. Retrieved from <https://deafblindontario.com/wp-content/uploads/2019/02/DeafBlind Ontario Services - A Canadian Perspective on the WFDB report - FINAL -rev Jan 22 FINAL-s.pdf>.

DeafBlind Ontario Services. (2019b). Stakeholder Consultation Project. Available online https://deafblindontario.com/wp-content/uploads/2019/10/2019_Stakeholders_Consultation_Report_FINAL-s_1022047.pdf

Jaiswal, A., Aldersey, H., Wittich, W., Mirza, M., & Finlayson, M. (2018). Participation experiences of people with deafblindness or dual sensory loss: A scoping review of global deafblind literature. *PLoS ONE*, 13(9), e0203772. <https://doi.org/10.1371/journal.pone.0203772>

Statistics Canada. (2018). Canadian Survey on Disability 2017: Concepts and Methods Guide. Canada.

Wittich, W., Jarry, J., Groulx, G., Southall, K., & Gagné, J. P. (2016). Rehabilitation and Research Priorities in Deafblindness for the Next Decade. *Journal of Visual Impairment & Blindness (Online)*, 110(4), 219.

World Federation of the Deafblind. (2018). *At Risk of Exclusion from CRPD and SDG's implementation: Inequality and Persons with Deafblindness*. Retrieved from <http://www.wfdb.eu/wp-content/uploads/2019/04/WFDB-global-report-2018.pdf>

Janinne a University Student Who Was Born Deafblind

JANINNE

AND

**SANDRA
SAMARA PIRES
FARIAS**

Janinne:

I am a Brazilian, a pedagogy student at the State University of Bahia, I'm 27 years old and a congenital deafblind person. I was born in 1992, from an extreme preterm labor of twins. I have a

family that has always treated me with equity. I was never considered "the poor one" due to my disability. That attitude has contributed with the construction of my identity and personality as a resilient person and a fighter.



Twin sisters Janinne and Jessica.

Samara:

My name is Samara. I'm Janinne's mother. I've graduated in Pedagogy and I've taken a specialization course in Special Education to support her path. Now I've also taken a master's degree in Education.

Janinne:

Well, I'll start my story in 1993 (Childhood Education) when I studied at the special school for the deaf. That's where I started to develop my autonomy. I had orientation

and mobility classes and I discovered various textures, and I could share experiences with my deaf colleagues.

Samara:

It was the first step for her educational life. I received all the initial guidance aiming Janinne's participation in the family life, in the organization of her everyday life: how to prepare her own food, bath time, time to go for a walk, among other lessons that served as a basis for her autonomy.



Janine and her twin sister with their teacher Eliane at Crissol school

Janinne:

I've continued studying in a special class for deaf students until 1998. That's where I've learned Brazilian sign language.

Samara:

I volunteered at that school during that time, as a mom. I learned sign language to teach Janinne how to communicate. At that time, I participated in a seminar on deafness in Rio de Janeiro, where I sought information on deafblindness. A while later, during the 2nd congress on deafblindness in Sao Paulo, I could learn how several deafblind persons communicate. I asked for support at Grupo Brasil, Ahimsa and Adefav, and we founded the parents' association. I dedicated myself to improve in sign language and Braille. I also took an interpreter and guide-interpreter course.

Janinne:

In 1999 we moved, and I started studying at another school. I studied during the morning

with blind students and I learned how to read in Braille. In the afternoon shift, I had classes with deaf persons. My mother was the teacher.

During the elementary school, I went to another school that followed the integral education approach, and there was a multifunctional resource room, and I was accompanied by a guide-interpreter.

Samara:

In this new city, I looked for other deaf and blind children. I've visited all those families to ask what their expectations were related to their children's school lives. I addressed the authorities to ask for a space to start educational services for persons with disabilities in that municipality. I've started working at as a special class teacher, with blind students during one shift and deaf students during the other shift. Janinne studied all day long and had contact with both deaf and blind persons.

INTERVIEWS



Janinne (around 7 years old) in the classroom, at Escola Municipal do Parque.



Janinne among her high school friends.

Janinne:

In 2010, I attended a teacher preparatory vocational high school course. A new reality. A fresh start! There were many challenges, mainly to hire a guide-interpreter, but also fighting for accessibility, training for teachers, the contents, resistance in curricular flexibility, and internships, sensitization of colleagues and school community convincing them about my possibilities and rights.

Little by little, everyone at school started to help me overcome all the obstacles. These were wonderful moments with my colleagues, beautiful friendships, and complicity.

Janinne:

In 2014, when I finished high school, I already knew I wanted to study pedagogy. In my first attempt to enter higher education I had all the special assistance needed to take the exam but, unfortunately, I didn't pass in any college. I was very sad with the news, but with the encouragement of my family and friends, I rose up and tried again. That was when I took the entrance exam for the State University of Bahia and got approved. I remember it was a wonderful feeling. I cried, I screamed in joy.

Considering that I was the first congenital deafblind Brazilian person to go to the university, I was the subject of newspapers, magazines and even state and national television programs. I introduced myself to the group that would accompany me during this walk, talking about my disability and the importance of having conquered that space.

Samara:

First, we had a meeting with the University to understand what would be necessary in terms of material, professional and infrastructure resources, which would guarantee not only Janine's admission, but her permanence in the institution during graduation. I provided an awareness activity on deafblindness and specifically about Janinne to her classmates. As an extension project, I offered a training course in sign language, for her classmates, teachers and staff members who wanted to participate, so that there would be no communication barriers from anyone with Janinne.

Janinne:

The semesters passed with new challenges, different ways of working, teachers who

contributed significantly to my learning. The academic routine has changed my whole life. I spend more time at the University than at home.

It's time for full dedication and joy, but also time to face stress and disappointments. And I'm bound to say: it's also time for achievements, political struggle and resilience.

Problems also arose, mainly regarding communicational accessibility. We had to fight in defense of my rights. Administrative issues regarding difficulties in hiring a guide-interpreter should be mentioned. It got to the point that my classmates stood by me when the University denied me the right to study while not hiring guide-interpreters. My classmates created the #SOMOSTODOSJANINNE (we are all Janinne) movement. As a result, the University hired 3 guide interpreters and a Braille writer, in addition to implementing a specialized educational assistance room.



Janinne holding a #SomosTodosJaninne movement pamphlet.

■ INTERVIEWS

Samara:

At that moment, Janinne's absolute autonomy pursuing her rights and respect, I noticed that this class is different. It is where competent professionals with an inclusive teaching practice are emerging.

Janinne:

Now I'm taking the seventh term at the University and I continue fighting for my rights and for the rights of those who will come after me, so that they'll find a pathway.

The next steps are already outlined in my methodical head: Master degree, doctorate (PhD), job, marriage, children and being very happy are some of the wishes that I intend to realize over the years. I'm sure that all the experiences I've had so far have helped me to be a better person, a shrewd adult, a loving daughter, an eternal student and will make me an excellent professional in the future. The processes of communication with people and the world through touch made me see much more than two eyes would ever let me see.

Rehabilitation Has Given Me New Opportunities

CFD's deafblindness counsellors offer the rehabilitation course 'Come Again!' for people with acquired deafblindness (Fact Box 1). The focus of the course is on life adjustment and the psychological aspects of living with a disability that affects two of our most important distance senses: vision and hearing. Not vision or hearing but vision and hearing. Both.

Fact Box 1:

Deafblindness is a combined vision and hearing loss that is so severe it is difficult for either sense to compensate for the other. Deafblindness is thus a specific functional impairment in its own right.

Deafblindness limits person's ability to participate in activities to varying degrees and prevents them from full involvement in social life. The functional disability affects person's social life, communication, access to information, orientation, and the ability to travel independently and safely. In compensating for the combined vision and hearing loss, the tactile sense takes on a particularly important role.



BETTINA UGELVIG MØLLER

CFD
COMMUNICATION
OFFICER

'It is a lifelong grieving process. The fact that I'm functionally deafblind is not something I think about every single day. It also isn't every day that I think about how tiresome it is. But sometimes it definitely gets to me,' says one of the course participants, Heidi, a woman in her 40s with a husband and two teenage children. Fortunately, she acquired some helpful tools and met new friends in the course *Come Again!*

Among other takeaways from the course, she mentions that her new tools have helped her realize that life is not over, even if daily life may look difficult. When she started the *Come Again!* course, she was going through

Important Friendships and a New Network

Heidi was born with a hearing loss and was diagnosed with progressive vision loss in 2008. *Come Again!* was the first time she met others who face similar challenges. The course had six participants in total. Although they did not know each other beforehand, they got so close that they are now continuing to meet in a network group.

'This was the first time I took part in something related to my vision. Not that I hadn't wanted to, I just hadn't been ready. I was not ready to take a close enough look at myself to see how much I was struggling.'

Her deafblindness counsellor reached out at the right time, when she was ready and needing new inspiration for tackling some of her daily challenges. 'I was at a point where I was telling myself, *So now I can't do this. I also can't do this anymore.* If I wasn't just going to end up in a chair in the corner, declaring myself utterly useless, something had to happen.'

Rehabilitation with a Focus on Emotions and Psychology

The emotional and psychological aspect is a key component of the rehabilitation course, which consists of three two-day modules. A psychologist with in-depth knowledge of deafblindness gives presentations throughout the course, and that is very significant for the participants.

The final house (Fact Box 2) – and thus the final course module – was particularly significant for

a rough time in her life due to her deafblindness. She was often overwhelmed by a claustrophobic feeling of being trapped inside her own body, and that scared her. 'After the course I am closer to coming to terms with the fact that this is my life. I am also getting better at saying it out loud and explaining it to others. I actually have a much more positive outlook on life and my options after the course,' she says and adds,

'My entire catalogue of opportunities and inspiration has expanded a lot. For example, I am much more aware of how I can use my tactile sense.'

When Heidi showed up for the first course module, she soon realized that she had worse vision loss than any of the other participants. She was the only one who used a white cane, and she was also one of the oldest members of the group. That made it hard for Heidi to be completely open about just how painful life was for her, and how tough she felt things were. She wanted to spare the others. She talked this over with her deafblindness counsellor, and together they agreed that she should engage in the course on exactly the same terms as the others and that she should not hold back.

Although the group members were in very different places in life, they were still able to help each other. 'Of course, it has to do with how open everyone is willing to be. We all happened to be very willing to share. I think all of us, without exception, had been missing this sort of forum. We all needed someone to relate to, and every time we met, we could feel the tension and the wariness gradually lifting. We relaxed in each other's company.'

Heidi. In her own assessment this was due to a combination of factors: it was the final meeting; by now, the participants knew each other really well; and the module involved the people close to them. Together with the presenters, the participants had made the course a pleasant forum – and even if they felt drained of energy when they came, they always ended up leaving with renewed energy, spirit and drive.

Fact Box 2:**THREE MODULES: THREE HOUSES**

The AV House: about hearing and vision and participant's personal experiences living with vision and hearing loss

The Energy House: about personal energy, strategies, the use of assistive aids and how to maintain balance in life, for example by means of yoga and mindfulness

The Network House: about communication and relations with family, colleagues, friends and other people in each participant's personal network.

'In the third and final module, the people closest to us joined the course for the first couple of hours. That affected me deeply. It became clear to me how differently we all handle this, and how differently we go about involving our families in the thoughts we grapple with,' says Heidi.

'I realized there should be a much stronger focus on family. This isn't a disability that only affects me. It has a huge impact on my family too. Sometimes we overlook that.' Heidi thinks of the 'forbidden' and shameful thoughts others sometimes have because of the limitations imposed by having a mother, a spouse, a daughter or a friend who is living with deafblindness. These are difficult emotions to handle, and that was an important topic during the final module.

'In the group, we agreed that the psychological aspect was precisely what we needed to explore together. It's a tough subject, and we needed concrete tools to help us navigate in

our challenges and involve the people around us in a good and constructive way.'

Heidi has become very aware of the different roles she has in life – as a mother, a wife, a daughter, a colleague, a friend – and how she should communicate in these different roles.

'I try to get better at striking the right balance in my communication, and in that regard I have learned a lot from the course.' She mentions that her family should be able both to offer help and to respond in a relevant and appropriate manner when she asks for help.

Before the course, the mutual expectations did not always match, Heidi explains, even though she and her husband have always had good communication. Several years ago, they vowed always to maintain a healthy balance in their relationship, making sure he did not become more of an assistant than a husband. They continue to work on that – now with a new set of approaches after they have both taken part in the course.

The white cane was my Entry into the Group

One of the most important assistive aids in Heidi's everyday life is her white cane, and she never goes anywhere without it. It plays an ever-greater role in her life, and today she cannot imagine doing without it. But it was a big step for her to give in and become a cane user, and today she wishes she had had someone in her life who might have introduced her to the white cane sooner. Based on this personal experience she deliberately brought up the issue of the cane

in the course, where she was the only cane user.

'I spent a lot of time in the group talking to some of the others who really needed to use a white cane. I think I helped inspire them to get one. The white cane gives you a sense of security because it sends a signal that this is something I'm having difficulty with. With your cane you're letting the people around you know that you have a special need. And

■ INTERVIEWS

that can be very challenging and a big personal step.'

In addition to bringing her own personal experiences into play in the course, to the benefit of the other participants, Heidi also benefited greatly from participating and becoming part of a group of people who face the same challenges she does.

'There are so many things I thought I would have to give up. I used to be very creative, but I had sort of given that up because my vision is so poor now. But in the course, from talking with the others, I realized that I can still be creative, even if it's at a different level or doing different things. There is still so much I can do and so many areas where I can contribute,' says Heidi.

Interview with Alexander Suvorov, a Participant of the Zagorsk Experiment

Alexander Suvorov is a deafblind psychologist and poet. Born in 1953 in Frunze (Kirghiz Soviet Socialist Republic). Graduate of the faculty of psychology of Lomonosov Moscow State University. Ph.D. in psychology, Professor. Honorary international doctor of Humanities, Susquehanna University (Pennsylvania, USA), a full member of the International Academy of Informatization (the Associated Member of the United Nations). Awarded the commemorative medal dedicated to the international year of volunteers, established by the UN General Assembly (2002). Lives in Moscow.

Alexander Suvorov has often said that he lacks live communication most of all. The reason is that he is almost totally deafblind, however, he still teaches, though quite a bit. And he is so happy to have guests.

His life worth writing books and making films. Suvorov is probably

the most famous living deafblind person in Russia. He is a participant of the famous "Zagorsk experiment", during which four deafblind people (Suvorov, Sergey Sirotkin, Natalia Korneeva and Yuri Lerner) mastered the full course of MSU, and two – he and Sirotkin – received scientific degrees.



**VLADIMIR
KORKUNOV**

PR MANAGER,
CO-NNECTION,
RUSSIA

V.KORKUNOV@SO-EDINENIE.ORG

We met with Alexander Vasilyevich in February 2020 in his apartment in the North of Moscow. The door was opened by Oleg Gurov, Suvorov's caregiver, and friend. I could not imagine that the conversation would last for three hours, and there would be as much said as not every life can hold... Suvorov turned out to be an incredibly interesting conversationalist. I sent questions to his Braille display via a flashcard, and he read them aloud and answered them immediately...

– Alexander Vasilyevich, you lost sight at the turn of childhood, when a person is not always aware of what is happening to him... Do you remember the "sighted" world?

– Whether it's a sighted world or a blind one, it's hard for me to judge. First, I still had light perception. Second, I don't know if I've ever fully seen it. I have a hereditary disease Friedreich's syndrome. Vision, as well as hearing, gradually went down. For a while, my parents didn't notice it. And then they found that I was looking for things with my hands and dragged me to the doctors.

– What do you remember from the colored and sighted world?

– Nothing. Colored - definitely not. Only light and dark. I remember my mother, but only by touch. I had no visual images of my mother, only tactile ones. Dad – even more so. I wasn't that close to him.

Generally, visual episodes are hard for me to remember. Well, here it is. My mother is taking me from kindergarten. I was crying about something. There are tears in my eyes. Evening. For a long time, I could distinguish the road, its right and left sides, the edges. This is not the case now.

– How did you learn to navigate in space? How were you able to overcome blindness in the everyday life?

– The blindness was not total. Light perception remained. It was better in my childhood, but now it's almost gone. At the weekend, I wandered down the street. I saw the road: sidewalks, trees, bushes, not in color, of course, but in contrasting light perception.

Up to university life, I did without a cane. And when I fell down the stairs there

(fortunately, there were no injuries), I realized that I couldn't go on like this, and the next day I went to get a cane.

– You lost your hearing at the age of nine – as a child, too. The sound didn't disappear immediately?

– My hearing has been worsening since I was born due to the same Friedreich's disease. Its peculiarity is that it affects the spinal cord, disrupts the work of the back and side pillars. This leads to complications in the brain-on the auditory and visual nerves. Their atrophy occurs. Since the disease is obviously hereditary, I was born sick. It develops over a lifetime, but very slowly. First, they noticed progressive blindness. Then deafness. Just as with my vision, my problems with hearing were established when they noticed that I started asking questions or not hearing words at all.

I remember my father asking a question. He asked once. Asked twice. Asked five times. And I still couldn't figure it out. He freaked out and was going to physically abuse me. But mom realized what was happening and stopped him. The doctors warned her about my future hearing loss.

For a long time, I understood the spoken language of a person standing or sitting next to me. Up to 14 years old. Then I stopped understanding spoken language completely. Noise hearing persisted for a long time, especially high-frequency one. Now I have sensorineural hearing loss – I can only hear the noise directly in my ear. And if someone is talking nearby, I don't hear.

– Were you afraid?

– There was no fear that I was blind and deaf. It's not about childish fearlessness. It's about the gradual process. I hardly noticed it... but there were other fears. Like many children, I was afraid of the night. I saw sparks and snow dots, and I was afraid. And I hid under the covers.

– Another stereotype. It is said that the deaf often hear a hum (phantom sound) in their ears. Have you ever had one?

– I hear this all the time. And it's not a phantom noise. It is the sound of blood pressure. I'm hypertonic. The philosopher Felix

Mikhailov became almost deafblind at the end of his life. He wore a hearing aid and strong glasses. He told me that he heard songs in his ears. He joked: “Well sing these devils!”. He also had heart disease and suffered from several heart attacks.

– Tell us, please, how do you get visitors? Before, when someone rang the doorbell, the light in the room began to blink brightly? And now?

– There’s a fan now. So, I ask everybody to call for a long time and continually, then I can feel the movement of the air. Previously, on the contrary, I asked them to click often many times, and then the light sparkled with bright flashes. But now I can hardly see it.

My light perception had been changed from childhood to old age. It was not a constant, but a variable. I have half a percent of my vision left. This condition is called almost complete blindness.

– How well can you hear now? Can you hear your voice through the headset¹?

– I can’t hear the voice, but there is such a possibility with the help of special speakers. But it will depend not on me, but on the device.

I have sensorineural hearing loss. The peculiarity of my hearing is that it is high-pitched. People who are Deaf often retain low-frequency hearing, but I have the opposite. So I could hear the high-pitched sounds, but not the low-pitched ones. And a gap in the speech range – from 1000 to 3000 Hz.

I don’t like modern hearing AIDS – they are somehow foolishly configured. Back in the 80’s, I had hearing AIDS with wheels that let me adjust the volume. If it was too loud, I turned it down. So I could hear music in a concert hall or a park. I really love wind orchestras!

And the new devices are made so that when the battery starts to run out, the volume is saved. And it can’t be regulated! As a result, I might hear a voice, but I don’t understand a damn thing. And the concert hall will be full of howls.

– What music do you like best?

– I have been in love with wind orchestras since childhood. Getting to know the first

one was very funny. I was a very little kid. On The Railroad Worker’s Day, my mother took me to a solemn meeting (she worked on the railway) and a festive concert in the summer cinema. And the Frunze branch of the railway had its own brass band. I was very interested. We sat down right in front of it. And when the orchestra started playing the anthem of the Soviet Union, and you know how it starts (sings. K.). This is the first “AAAAAAA” when the orchestra thunders and rumbles (hits the arm of the chair. - V. K.) and when I heard that first long sound, I screamed: “There’s going to be a thunderstorm!” and dragged my mother under the roof. Mistook the first note for the thunder! I was forced to calm down, explained that this is not a thunderstorm, but an orchestra. After that, I started to listen carefully. And since then, wind music is my favorite.

I have a lot of marches and waltzes in my music library. There are also funeral marches. And dance ballroom music. Johann Strauss is my favorite.

I also love symphonic music. For example, Shostakovich’s symphonies. But they are difficult to hear – a very large range of volume.

– In 1964, you were sent to the Zagorsk boarding school for deafblind children (then it was called the orphanage for the deafblind). At the age of 11, on September 13. How did you meet the world of the boarding school and its students?

– It was difficult. I was an outsider at school for the blind. And I set my mind on continuing this story. With adults, it was immediately well. I noted their kindness. And I was afraid of the young guys in advance.

Since I arrived without medical papers, I had to spend the first night in an isolation ward. Other guys – Sirotkin and Lerner-found out about the new guy. We went to the isolation ward to get acquainted. At first, we communicated through a Braille display. I took a long time to master fingerspelling. Slowly memorized the handshapes, slowly perceived. And I began to communicate freely only in the summer of 1965.

So the guys wrote through the display, and I read. And answered through the display.

¹ A special device that is being developed for Alexander Suvorov.

In the first days, there was a conflict. I was even boycotted! “We don’t want you,” they wrote on the Braille display.

I missed home, my mother. Cried at night. My whimpering made it difficult to sleep for the nanny. The bedroom doors were open. And the nanny’s place on the couch was not far away. She had no right to use force against me. She woke up Sirotkin and Lerner. Sirotkin put his hands on my chest. As if strangling. When crying, the breath is choppy. And the chest rises and falls. And so he “calmed” me with blows to the chest, until I began to breathe in a smooth flowing manner with a great effort.

Yes, the torture continued.

This is how I spent my first months in Zagorsk. But there is a silver lining. I read around the clock. This was also fought. At night, as you know, you are supposed to sleep, not read. They tried to take my books away. God knows what tenth sense I felt the approach of the “night guards” – the paramedic and nurses. I can feel the breeze – and I hid the book between the beds or the bed and the wall if I slept against the wall. Hid “standing”. And the guards didn’t like to go under the bed, they couldn’t reach the books. As they leave, I go back to the book.

I read under the cover for a while. But they quickly figured it out. They find something solid and take it away. So I began to read openly, and if I feel a little breeze, I use the described method. But in general, I admitted the orphanage well. Like a good place.

– Professor Ivan Sokolyansky was one of the first in the USSR to start teaching deaf-blind children. In 1923, in Kharkiv, he created a school-clinic for them. Among his eight pupils was Olga Skorokhodova...

– Correct you. In parallel, there were two groups: in Kharkiv – with Sokolyansky, and in St. Petersburg – with Augustina Yarmolenko (she also had eight children). Sokolyansky was not famous for being the first to start, but for the fact that he achieved the greatest success, revolutionized the training of the deaf-blind, and became Skorokhodova’s teacher. And she is the first deafblind woman who received higher education and defended her Ph.D. in the USSR. Her book “How I perceive,

imagine, and understand the world around me” is psychological. And my book “Meeting of the Universes, or deafblind aliens in the world of individuals without sensory challenges”, in fact, is its continuation.

– Did you communicate with Olga Ivanovna?

“Yes, of course. She came to our orphanage – she was one of its founders together with Meshcheryakov. He brought her. She lived in sickbay for several days. And was “occupied” by the older guys. Natasha Korneeva was especially close to her. But Sirotkin and Lerner, too. It was almost impossible for me to break through this cordon.

– Can you remember any episode related to it?

– When we were already students, Korneeva went away on some business. And she asked me to sit with the old lady. And then says: “I want to pee.” I was confused. What is “pee”?

Then she began to examine me more closely with her hands. “Sasha?» – «Yes». We laughed a lot about it. Especially Natasha, a person with a great sense of humor. Olga Ivanovna grumbled at her: “Why didn’t you warn him”? And she was laughing.

– There is a lot of talk about the conditions that were created for the “four” at Moscow State University. And textbooks on all subjects in Braille, and each has a supervisor...

– How else? We are blind! However, Sirotkin and I had one supervisor (the so-called secretary, interpreter) for two. It was more convenient that way. But the course was not adapted. We were only released from some subjects - mathematics, statistics, a foreign language.

The University allocated money: 2000 rubles a year for reprinting textbooks and special literature. Some of the books were published in Braille to us. For example, Gorsky’s textbook on mathematical logic. Or on the history of the CPSU-there was such an exotic subject. On scientific communism, on the history of philosophy, on all these “super necessary” subjects. But I had to reprint Rubinstein’s “Fundamentals of General psychology”. “Problems of mental development” by Leontiev, too.

But there was enough money. One Braille sheet cost 20 kopecks. The ruble – five worksheets. 2000 rubles – 10 thousand sheets. And the sheets are like this (shows more than A4. - V. K.). We even ordered books for ourselves! I, for example, ordered “Vasily Terkin”, “Notes of the gray wolf”, “ Smile of fortune»...

How were the classes? The teacher or the guest is sitting with a keyboard, typing on it. And deafblind people with so-called “tactors”, everyone has their own. How many tactors, so many of us – or vice versa. Each device has a Braille keyboard. And we understand what they want to tell us.

Then the teacher calls someone to answer, he or she turns on the fan standing near one of us, like saying “To the blackboard, please”. We spoke with our voices and simultaneously typed on a Braille keyboard. The rest of us had the text of our answers on the keyboard. Yes, the conditions were perfect. They did everything they could.

– Why did you decide to continue your education?

– We didn’t decide – it was decided for us. This was a continuation of the “Zagorsk experiment”. The Psychology Department was interested in our education. That’s where we were gathered. When people ask me why I chose psychology, I usually laugh. It was the opposite. Psychology chose me.

– Was it your desire or Alexander Ivanovich Meshcheryakov’s (teacher of A. Suvorov) to get a degree?

– He and Ilyenkov dreamed, of course. But Meshcheryakov died in 1974. And we graduated from the university in 1977. Ilyenkov died soon after. Sirotkin was “made” by his wife. I made myself – with the help of the laboratory of academician Alexey Bodalev. I was interested in it and worked hard.

I wasn’t particularly interested in degrees! It was more important to communicate the experience and knowledge, to continue the “Zagora experiment”. And then the Soviet Union collapsed, and there was nothing to live on. In the 1980’s, I had enough for 130

rubles a month. I lived alone, without a family. I could help my mother. I used my own money to fly to visit her in Frunze.

In 1986, my mother and children moved closer to Desnogorsk. This is the Smolensk region. My father was dead by then. Gradually, I moved everyone to Moscow. First, my brother, a year before my mother died. And then my sister. All three of them are in the cinerarium now...

In general, after the collapse of the USSR, I needed urgent career growth, and for this thesis defense. So I asked the Bodalev group for help. By that time, I had already formulated a topic – “Self-development of the individual in an extreme situation of deafblindness”. By December 1993, I had passed the qualifying examinations for the Candidate’s degree. That’s when they joined: Vilen Chudnovsky, Natalia Karpova, Bodalev himself. Irina Salomatina re-typed literature for me. Generally, my defense is a collective victory. Not just my personal one.

I defended my Ph.D. on March 31, 1994. From Junior Fellow, I became a research associate. In September of 1994, I was offered to prepare for my doctorate wasting no time.

The offer came in handy. I had a huge manuscript that I finished in March 1993. It was called “Problems of concrete humanity”. 20 printed pages, 500 typescript pages! They helped me reproduce it and made photocopies. The manuscript became both of my dissertations. Ph.D. was 180 pages. The rest became a doctorate thesis. I defended them as a scientific report. With the support of the battalion (smiles). I became a doctor of psychology on May 21, 1996.

My mother was not on the candidate’s defense, she was in the hospital. But in the doctorate’s defense, she was and was the main character. The scientific public came up and congratulated her on a son that she could be proud of. My mother told me: I sit, they say, I don’t know anyone, and everyone hugs and kisses me.

Naturally, both of my dissertations are devoted to her. She died in February 1997, on February 4 (with sadness).

– **How light and touching it sounds! And tell me how did you start teaching? Did you want it or did someone else suggest it?**

– They suggested and I wanted to. I have been working with children for almost 15 years, since 1981. That's when I fell in love with them. Was proud of them. Liked to chat. And to teach! I wanted to be useful to them in some way. When I got my Ph. D. I started to work at the Faculty of Defectology of Moscow State Pedagogical University in the South-West of Moscow. The bad thing was that I was given a group of hard-of-hearing students, and this is just what they call "hard-of-hearing", in fact, they were Deaf. And I don't know signs. How can I teach? I started writing lectures and printing them. I brought two copies of the printout to each class. Still, cartridges are expensive. I did everything at my own expense. And two semesters was this way.

Before the second semester, my mother died. But I didn't stop working. Then came the draft of my forthcoming book – the lectures on collaborative pedagogy, which was published in another university, Boris Bim-Bud.

At MSPPU, I started lecturing as an hourly employee. And in general, wherever offered, I did not refuse! Now I am quite an experienced educator. Spitting from a top on all the standard methods, I do everything in my own way. I dump the course literature on a flash drive for students.

At first, I took exams like this: I talked to each student for a long time. I had a whole day of tests. And now everything is fast. They don't give it to me, I give it to them. They ask questions, and I answer them. That is, in fact, it is a consultation. And then Oleg (a caregiver and a friend of A. S. Suvorov. - V. K) home free: everything is fine, all credit!

That's what an educator I became. My reasoning is simple: students are confused, overwhelmed with courses. It's impossible to learn everything in each course. What they would learn within my short classes? It is better to communicate like a human being.

– **For a person who is not familiar with the life of an individual having vision and hearing loss: how, as a deafblind person who is practically totally ...**

– I live worse than totally deafblind! I am in a wheelchair too!

– **Excuse me. How do you live alone?**

– Eat, sleep. Eat, sleep. That's how I spend my days (laughs)! And in the interval, an iPhone or this device (shows on the Braille display. - V. K.), or music. Friedreich's syndrome has completed the whole list until my anility. There is the list: injured spine, deaf years, blind eyes, and ophthalmic nerve atrophy. Backaches are very strong now. I stuck in a wheelchair because of Friedreich's syndrome. Also, I'm weather-sensitive, I suffer a lot.

– **When did you focus on art for the first time?**

– When I was 3. At first, there were "imagination" games. Then reading joined them. Also, I loved to play with geographical maps, every time thought up something new! The first attempt to write a poem happened when I was 8 or 9. Next was in April 1967. Since that time I've been writing continuously.

I'm a bookish person! More than any other. This is how I make sense of myself. I'm worried about some problem, I can't solve it – so at least I'll think about it! This is easier to do in the text. But there is a downside - I'm a terrible chatterbox and can't keep secrets inside. So, I write about everything.

– **What, in your opinion, is the most important thing in a literary text?**

– Accuracy. I resolved this issue for myself as a teenager, at the age of 16-17. Everywhere, in any text, the most important thing is accuracy. And in science, too. But the accuracy varies. In a scientific text, it is the exact wording, and in a literary text, it is images that accurately convey what the author wanted to say.

– **What is poetry for you?**

– No, poems do not bleed. They are that proper blood. Effusion of blood.

– **Could you mention several national and foreign poets you like most?**

– Among Russian authors from adolescence and for the entire life - Tvardovsky. It's even a shame to call Pushkin -one cannot live without Pushkin. He is beyond comparison. In the second place - Nekrasov. I love him so much! Also Kedrin. Зарубежные? Goethe's "Faust", I suppose. And Béranger with his "Songs". And, of course, "The Song of Hiawatha" by Longfellow in the translation by Bunin.

Seize the Moment and Reinvent Our Lives

The changes that the world began to experience caused by COVID 19 impacted the whole world. Each of us has had to face situations and challenges to fundamental aspects of our lives like health, economy, education, and society. The isolation which seems the best protection against the threat of spread of the virus is a hard solution for humans who are social by our very nature and take courage and strength from closeness and being together.

For people with deafblindness whose lives are connected to the world through physical contact, these effects are multiplied and make the simplest aspect of life immensely challenging. Deafblind International, through a note from its president, Frank Kat, invited us, the deafblind community, to find ways to meet and stay together. Frank Kat told us, "Deafblind International is about connecting. Connecting persons with deafblindness, parents, teachers, caregivers, therapists, researchers. It is also about solidarity as a community, especially now. Communication is crucial in these times, so I invite all of you to use our networks: our special Facebook page, website, Instagram or other channels. Actively share and exchange best practices and solutions." Those

words allowed us to see a great opportunity generating a space to share and nurture our practices offer the maximum possibilities in a time that required great changes in our homes, community and throughout the world. This is how our Coronavirus group was created on Deafblind International Facebook.

In reviewing the messages and sharing on this page, we reaffirmed that our shared experiences resonate across barriers of language, geography, and culture. Much was shared by families, people who are deafblind and professionals and organizations that provide services. We watched as people found information, support and solace from this site and wanted to capture some of the ideas and lessons that have emerged.

Experiences from the Voice of People with Deafblindness

"I am fighting life to live despite the hardships" (Nitin Taneja)

There are many international efforts that share information and create awareness about

GRACIELA FERIOLI

DBI COMCOM
MEMBER

G_FERIOLI2000@YAHOO.COM.AR

YVETTE GALLEGOS

DBI
COMMUNICATION
AMBASSADOR

YVETTEGALLEGOSB@GMAIL.COM

NAMITA JACOB

DBI
COMMUNICATION
AMBASSADOR

JACOB.NAMITA@GMAIL.COM

EUGENIO ROMERO REY

DBI COMCOM
MEMBER

ERR@ONCE.ES

EXCHANGE OF EXPERIENCE

the deafblind population and COVID 19. Regardless of the hard time, everybody is going through, this has been a great experience because a big network has been created. All of a sudden, teachers, parents and students from all over the globe have experienced very close communication.

Topics like cooking, washing clothes, writing, communication, and language are just some of the areas where this wonderful community has shared experiences, thoughts, and worries.

We have also learned about the worries of young adults and adults with deafblindness since they shared that their communication process has become “at risk” because they “need tactile closeness to communicate”.

They also realize that they are “at risk population”. But at the same time, they let us know that they are not putting their heads down. They are a community used to struggle and not letting go at the first frustration. They have said things such as “we need to use this time wisely” and “we need to seize the moment and reinvent our lives”.

One of the many strategies that this wonderful community has developed are questionnaires that will help to meet and identify needs, experiences, and worries from people around the world. It is amazing to realize that their needs are similar even though they come from very different places.

Experiences from Family Groups

“The family is a space for building freedom in diversity, where everything is possible when we believe and give opportunities.” (María Verónica Cajal)

Families who had their children living in residences have shared how difficult it has been, not being able to see their children and for people with disabilities themselves, this distance has been hard. There has been an important change in the interaction with the staff; now mainly via WhatsApp, mail, phone calls and video calls where they shared the changes that are implemented in the operation of each residence and service. For example, a residence created in the Netherlands

One of the Key words is ADAPTATION. This involves looking and finding different ways of communicating, different ways that add to the strategies used up to now. Also, it means to have technology as a great tool to create and share information, experiences, and resources that could be shared and used through the world of people with deafblindness.



Zamir Dhale from India sharing in first person his experiences during COVID 19

by parents of people with deafblindness shared with us what they have made some adaptations to cope in these new times by creating different activities like working with wooden sticks of 1 ½ meter and decorate them; another activity is they created a sort of model shop to let the deafblind person know how the interior of shops was changed due to the coronavirus.

Families in their turn stayed involved in the centers supporting them in whatever way possible. They participated in creating materials the center required, like face-masks, and supported them in finding resources from the community, so that the centers

may manage in spite of the increased costs caused by the pandemic.

Another very interesting point that families have shared is the improvement in integration within the family. With everyone at home, all members are participating in activities that involve and include everyone. This has had a very significant impact, particularly for those family members who were previously less involved with the member who has a disability. Families shared how they tried to maintain the routine and how difficult it was for them to express to their children having to stay at home, not go out or go to school. "It is a challenge to be able to keep them active at home."

Families tell us that they receive advice from the schools to carry out activities at home and some programs reached out to siblings as well. Some parents spoke about learning from the training programs that were advertised and shared on the internet - for example, by World Blind Union and other organizations. They described that the present situation gave them the opportunity to learn and to do a better job. Other families, who did not have technological resources, and relied on services that sent tasks or materials to their homes. So, one of the most important things that has happened is the recognition of the parents and the day to day work. They have shared their family experiences by letting us go into their houses, sharing needs and accomplishments in these long days of quarantine.

We also learnt of the amazing strength and generosity of families who reached out to

one another and worked together in solidarity. The Group of Inclusive Families in Venezuela used social networks and virtual communication to provide guidance to families. They formed two WhatsApp groups that included professionals, people with disabilities and families and every Thursday since April 2020, different people shared ideas, knowledge and perspectives on topics ranging from Stress and Anxiety management to Families dance Zumba! The groups have over 400 members from many countries and who continue to participate actively to date."



Morita and her brother engaged in therapeutic activity with shaving cream.

Experiences Published on Social Media

What began as news reports of events in a foreign country suddenly started making headlines in many countries and before we fully understood what was happening, a pandemic swept the world! Newspapers, radio, television and, of course, the internet, have been flooded with information, resources and explanations. A lot of the information was not accessible and most not responsive to the questions and concerns of people who are deafblind and their families. Therefore,

a very important aspect of the Facebook Coronavirus Group that was created was the possibility that people shared resources that were relevant and that they had found useful.

Guidelines for protecting yourself in general as well as what to expect and how to prepare for testing or hospitalization were created with a deep understanding of the reality of being a deafblind person in a world where people providing emergency and critical

EXCHANGE OF EXPERIENCE

response services were likely to have no sensitization to their needs.

With everything changed for everybody, it was helpful for people who are deafblind, their families and their services providers, to see discussions on topics like safe engagement with intervenors / interpreter guides or how to cope with loss.

Families, caregivers and professionals wondering how to explain the situation to their child who is deafblind, how to help them accept new rules around physical contact, wearing masks or seeing people in masks and why their routines had changed so much, could access this site for ideas and information.

Lived Experience

Families and people with disabilities themselves shared their lived experience. The site has many posts that give us a chance

An unexpected benefit of the pandemic was the attention from mainstream press. The challenge of being deafblind in the middle of this crisis that requires social and physical distancing caught the imagination of several reporters and news articles appeared all around the world. Often powerful first-person reports were shared and for the first time, the diversity and amazing spirit of this community was made visible to the larger community.

The creation and sharing of resources is one of the great benefits of this pandemic. From planning for hospital visits to managing stress, from dealing with change to teaching new health practices; the guidelines generated will continue to be a great resource for this community.

to better understand the barriers, the strengths and the abilities of families and people who are deafblind.



Melanie and her mom Karina participating in Argentina Flag Day class via internet.

Conclusion

The sharing across all the posts make visible the incredible creativity, strength, and deep wisdom across this group. People who are deafblind opened their lives, their thoughts and their feelings, with honesty and openness allowing others to learn from their experiences.

Families demonstrate their own capacity to create solutions for themselves. They naturally restructure their environment, create communication strategies, and find resources from the people and things around them.

Bonding within families and between professionals, organizations, deafblind people and

families grew as each rose to the continued challenge. The site holds examples from across the posts of how each has adapted to this new reality, showing an essential strength of spirit that is inspiring.

As professionals from different parts of the world, we have learned and grown as individuals by reading and sharing through this

wonderful group of people. DBI has enriched us again, by promoting togetherness even in these adverse circumstances by letting us share our own realities and experiences with others. We have learned how people with deafblindness, families and their surroundings go through this COVID time... and sometimes even enjoying life.

Mission During Coronavirus Situation: “Put Something Similar Instead”

**MARIA
BÆRENSEN**

COMMUNICATIONS
OFFICER, ACTIVITY
AND HOUSING –
CDH, AALBORG,
DENMARK

MAHB@RN.DK

The staff at the activity department has focused on making everyday life as uninterrupted for the residents as possible, even though the setting was completely different than usual. This led to creative solutions, increased collaboration between departments – and it also led to extra focus on the core task.

Most of the professional routines usually performed by the staff changed overnight, when Denmark shut down in mid-March. But the coronavirus situation did not only bring dilemmas, challenges, worries and urgent changes. The special situation also boosted the creativity of the staff.

“We have taken a lot of measures to unite the community, even though we had to be together apart,” says Ina Nygård, who is an

educator in the activity department in Activity and Housing – CDH.

One factor that is crucial when working with people with deaf-blindness is “usually” – and to have a familiar structure that residents can navigate by in everyday life. But many things usually done were cancelled because they, in their usual form, would be too risky to carry out.

Rather Give the Party a Twist than Cancel It

“Thus, the focus has been on replacing “usually” with something that is similar which we could still vouch for professionally. For example, we usually have a large party in the woods every summer for the entire Activity and Housing – CDH. Instead we threw a party in the housing department’s courtyard for the people who live there – featuring social distancing and copious amounts of hand sanitizer. With live music and everything, and it was great,” says Ina Nygård.

“The housing department Danalien also usually hosts an evening party for the residents, usually attended by i.e. parents and guardians. But during the lockdown, there was a visitor ban. Well, the staff was then invited as guests instead. In their spare time. All dressed up and with a red carpet and everything that goes with a real party. It was marvelous,” says the educator in the activity department with a warm smile.

Extraordinary Goodwill

There were also other forms of extended cooperation between the housing and activity departments. Overall, Ina Nygård believes that the goodwill and flexibility has been extraordinary during the coronavirus lockdown. The staff has supported and covered for each other in times of illness and holidays, etc.

“We also started up a new tradition during lockdown. Every morning, we arranged a singalong with a popular, nationally broadcast TV show in the housing department before we switched to the activity department. It was a very big success,” says Ina Nygård.

The Creativity of the Staff has been Extensive

There are several examples of the creativity that the staff showed to make things as nice as possible for the residents. There were open air hairdresser visits in the courtyard. Greetings by mail were arranged between a resident and the people she missed but did not have the opportunity to see during the lockdown.

Usually, the residents from the housing departments are divided across three subdivisions of the activity department during the day. However, during the coronavirus lockdown each residence functioned as both regular housing and activity center in the daytime. The staff came up with alternative, tactile markings of transitions from “being at

home” to “being in the activity department”, even though both took place in the exact same rooms. Also, a lot of excursions out of the house were on the program, a visual diary poster was created, etc.

Ina Nygård has one particularly touching story from the coronavirus lockdown:

“One of the residents in the housing department passed away, and usually residents attend the funeral when they lose a fellow resident. But due to the coronavirus, this was not possible. Instead, we arranged a memorial service at the same time as the resident’s funeral, where we sang exactly the same hymns that they did at the service in the church. It was a nice experience.”

Not the Best of Times, nor the Worst of Times

“Overall, I think it has been some good months. Like everyone else, we had a strict framework to work within. We neither could nor would discuss that – we just decided to get the best out of that framework. It has not been too bad at all to slow down and get

more peace of mind – everything not strictly necessary was cancelled: meetings, courses and the like. We have had plenty of time to focus on the core task, and it has been good for everyone involved,” is Ina Nygård’s assessment.

Top Three Things to Learn from the Coronavirus Lockdown

- Be careful not to divide employees into too small, isolated teams. Some of the important discussion and sense of unity might be lost.
- When everything not strictly necessary is cancelled (e.g. meetings, training, seminars, etc.), there will be more time for the core task; better time for 1:1 work.

Something like that rarely comes back badly.

- In the long run, however, we need precisely the things that are not strictly necessary in a time of crisis. Professional development provides energy and job satisfaction. And it benefits the residents which is an important point!

How Innovation Is Bridging the Educational Gap Between the Living Room and the Classroom in Tanzania

GILL CARTER

PROGRAMME OFFICER, SENSE INTERNATIONAL

GILLIAN.CARTER@SENSE.ORG.UK

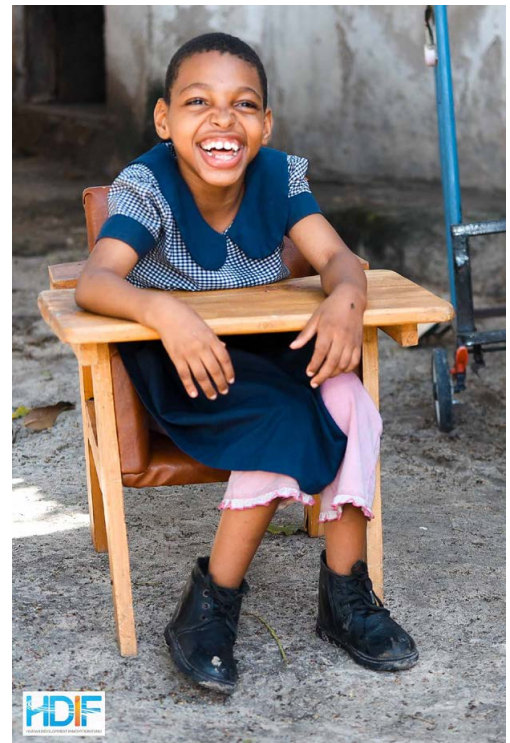
ISABELLE DE VUGT

ISABELLE.DEVUGT@SENSE.ORG.UK

BENJAMIN KIHWELE

The United Nation's Convention on the Rights of Persons with Disabilities (UNCRPD) states that inclusive education will only be 'inclusive' if the most marginalized children, typically the hardest to reach, are reached. Due to complex challenges with communication, orientation, mobility, and acquisition of information leading to difficulties in building concepts of the world around them, children with deafblindness/multi-sensory impairment (MSI) are often excluded from education. At Sense International we are working towards ensuring all children with deafblindness/MSI can enjoy their right to education so they can learn, earn and thrive in life. An inclusive education project by Sense International Tanzania that ran from 2016 to 2020 has done just that. With support from the Human Development Innovation Fund (HDIF) – a UK Aid initiative, the project impacted the lives of 163 children with deafblindness/MSI in Tanzania. The inclusive

education project used an innovative 2-step model to utilize the power of technology in education.



Angel, a girl with complex disabilities that has been supported to attend school through the project

Harnessing Technology for Inclusive Education

The first step in the model increased the uptake of home-based education for children with deafblindness/MSI. With on-going

support and participatory training, parents and caregivers followed a specialist curriculum to provide education and support



to children with deafblindness/MSI at home. Parents and caregivers were provided with a tablet computer which was pre-loaded with instructional videos and resources to guide them on how to provide quality support and education to children with complex disabilities.

Unlike one-off training, parents could watch and re-watch the videos until they felt confident with the content. Meanwhile, the tablets

also proved to be a stimulus for learning for the children who were intrigued by the tablet's functionalities and resources. In a world following the onset of COVID-19, it has become more apparent than ever that online content and technology is incredibly valuable. In a world where face to face contact has become ever more restricted, the benefits of having videos and online resources have been magnified.



Angel learning through a computer tablet

Teaching Assistants Support Children to Reach their Potential

Step two of the model focused on supporting children to transition from home-based learning into a classroom in a mainstream school near their home, with the support of a trained teaching assistant. Teaching assistants play a dynamic role in achieving inclusive education for children with deafblindness/MSI by providing one-on-one education, supporting children to perform daily tasks (such as using the toilet, eating

and playing), providing communication support, carrying out home visits to follow up on progress and assisting children to get to and from school safely. This component of the project worked to ensure children with deafblindness/MSI, who have traditionally been isolated and excluded from educational settings are finally given the opportunity to attend school like their peers.

Empowering Parents through Income Generation, Learning and Improved Support Networks



Kelvin, a boy with deafblindness being supported by his teaching assistant in school

At the start of the project, most fathers were reluctant to support their children to go to school. They thought it was not possible for their children to learn and many thought it was a waste of time. However, attitudes began to shift as parents started to see the benefits of the education being

Lessons Learnt

The factors contributing to a successful inclusive education project are multifaceted. Through this project we have learned that achieving inclusive education is heavily pinned upon the training of teachers and school staff. Furthermore, it is apparent that a conducive learning environment is

provided to their children through the tablets at home and the teaching assistants in the classroom. Theresa, a young girl with complex disabilities who was supported through the project, emerged top of her class during the *National Standard Four* examination. Her father explained:

"...It has been a long race to get here. Our daughter stayed at home with no hope of being enrolled in any school as she was denied admission due to her multi-sensory conditions. She could neither sit nor eat by herself. With support from her teaching assistant, when she turned 13, she was brought by the project to start Standard One in primary school. Now we are celebrating her being in Standard Five, marching forward to fulfilling her dreams of being a lawyer..."

With children engaged in school, parents and caregivers found they had greater time at their disposal now they were not caring for their children on a full-time basis at home. Parents were enabled to attend regular support meetings and to start income generating activities. They were empowered, both financially and socially. With more time at their disposal, parents were in a position to start businesses and earn an income. Meanwhile, parent support groups provided a forum for parents and caregivers to interact with others who shared an understanding of the everyday challenges and realities they and their children face. The project has proven successful in transforming attitudes so parents and caregivers are eager to maximize the potential of children with deafblindness/MSI.

needed, in this case through the allocation of teaching assistants to support children with deafblindness/MSI. Finally, the empowerment of parents and caregivers through technology to provide on-going, cost efficient and high-quality support should not be overlooked. The use of tablets has

successfully bridged the gap between the classroom and the living room, making education a reality for all, not only during the

unprecedented times of the COVID-19 pandemic but also beyond it.

For more information, contact: info@senseinternational.org.uk



Kelvin playing and learning with friends at school

Online Diagnostic Sessions for Families of Deafblind Children



ANNA DOROFEEVA

SPECIAL EDUCATOR, CONSULTANT OF THE COMMUNITY OF THE FAMILIES OF DEAFBLIND

ANNADDOROFEEVA@GMAIL.COM



JULIA KREMNEVA

CEO OF THE COMMUNITY OF THE FAMILIES OF DEAFBLIND

J.KREMNEVA@SO-DINENIE.ORG

During the COVID-19 pandemic, many families of children with deafblindness have found themselves in a situation of severe lack of different services. Although a lot of educational institutions managed to organize distance learning, this isn't the most efficient way for students with deafblindness to study and communicate. Besides educational institutions, social organizations have also experienced some problems. For instance, The Community of the Families of Deafblind is unable to organize special summer schools for families and children, Mother's School, which is usually held every summer in different Russian cities. Summer school lasts one week, during which families and special educators meet, participate in diagnostic sessions, discuss their issues, and find answers to their questions about the best ways to support and educate children with deafblindness.

The first day of Mother's School is dedicated to the diagnostics. On average, there are from 8 to 12 families and during the diagnostic day, each family gets about 40 minutes within which educators conduct a short diagnostic of a child, talk to parents, learn about the issues they want to solve and plan their work for the next days of Mother's School.

It was decided to try and modify the format of these diagnostic sessions and hold them online. Online diagnostics have the obvious disadvantages such as inability to communicate with a

child personally; unavailability of many diagnostic tools; and problems with establishing contact with families. At the same time, there are some benefits that are especially prominent during the pandemic. Families get the moral and educational support of the Community of the Families of Deafblind and special educators and they feel motivated to spend more quality time with their children. The online format also makes it possible to gather specialists from different Russian cities what is not always possible during retreats.

Two documents were created to collect data about a child before the diagnostic procedure. The first one is a questionnaire for parents (see Annex 1). There are a few questions that provide general information about a child such as a name, age, education, vision and hearing disabilities, etc. But mostly the questionnaire focuses on child's current level of knowledge and skills. For example, there are questions about the way a child explores new objects; about his communication skills, and how he orients in different places. In most questions, parents are asked to tick the appropriate answers and some questions suggest full written answers. Some parents noted that the questionnaire helped them to see their children from another point of view and realize how much they can actually do.

The second document is a list of topics for the videos that can help educators to get some sense of child's current level (see Annex 2). The list of videos is complementary to the questionnaire. Parents are asked to film videos that corresponded to the main sections of the questionnaire: communication, physical development, self-help skills, behavior, orientation and mobility, and academic skills. Parents don't have to make videos on all suggested topics; most of the time they choose only the ones that are important and correspondent to the issues they want to discuss during the diagnostic session.

After filling out the questionnaire and filming the videos, parents are asked to formulate their request in free form. They can elaborate on the most concerning issues and what they want to discuss during the session.

The diagnostic session lasts between one and two hours. Typically, there are three to five special educators, a moderator, and one or two members of the family. The sessions are held via ZOOM.

The session starts with a clarification of the family's request and its further discussion. If it is needed and possible a child can be involved. For example, specialists may ask a mother to show the way she helps her child to drink from a cup, or they can ask a child

to read, etc. The second part of the session is mostly devoted to the recommendations.

There are two main requirements that the recommendations should meet considering that the diagnostic session is held online.

The recommendations should be simple and feasible. It is common for many families to get extensive lists of recommendations and suggested exercises. At first, they feel motivated and inspired but after a while, it becomes apparent that no parent can conduct two or three lessons every day; there is no time or resources. The exercises our specialists recommend usually don't last more than 10 minutes and should be done 2-3 times a week. Some of the activities can be recommended to be done daily but they can last only 1-2 minutes. Also, we pay special attention to the tools that can be used. Usually, parents can use toys and household objects and do not have to buy any special equipment. Often they don't need to use any equipment at all.

In addition to some activities and exercises, some behavioral interventions can be suggested. Usually, it is about using a certain phrase or gesture or showing a certain reaction to the behavior. Another kind of recommendation is a course of actions for certain activities. For example, there were courses of actions for bathing, eating, dressing, etc.

When recommended activities may be linked to the already existing routines. This way it is easier for the family to include something new in their daily life without creating stressful situations for the family or the child. For instance, specialists often recommend involving children in the processes of cleaning or cooking that helps to teach cooperation and provides the child with more information about the world around him. It certainly requires some additional efforts to be made by parents, but at the same time, it's not a separate activity that would need special time and place.

After the diagnostic session, specialists send their recommendations to the moderator. Moderator's task is not only to collect all recommendations but also to format them and

■ EXCHANGE OF EXPERIENCE

then send them to the family. At the moment there are three forms of recommendations.

There are written recommendations with detailed explanations of exercises and interventions. Some parents prefer this format since they want to know exactly how and why they should do certain exercises and what kind of results they might expect.

Table of exercises (see Annex 3) contains a list of suggested exercises that are suitable for such format. There are three columns: tools, necessary for the exercise, short description of the exercise and frequency of its implementation. Parents are invited to print the table and put it somewhere they can easily use it for reference.

The third format is a three-month tracker (see Annex 4). Parents are invited to track how often they perform suggested activities. It is expected that by seeing that they are doing at least one thing a day parents will feel less stressed and more productive. Especially since most exercises are less than 10 minutes and should not be done every single day.

In the near future, we plan to gather families who have already been through the process of diagnostic and ask what format of recommendations has been proven the most useful for them or if there are any changes and additions they would like to suggest.

The recommendations are given for three months. After that, a follow-up meeting is held to choose new goals or to adjust the old ones. At the same time, if parents have some questions during the three months, they can contact the specialists for a short consultation.

With the end of the pandemic, it is planned to use online diagnostic sessions as a preparatory phase for Mother's Schools. This will help families and educators meet each other and gather some basic information about children. However, considering that there are very few specialists who work with children who are deafblind in Russia, the online format gives families from different parts of the country the opportunity to get expert help and support even outside of Mother's Schools.

Annex 1**Examples of questions from the questionnaire for families****Vision**

Describe your child's vision problem and how it affects his/her functioning.

Has your child been prescribed glasses? Yes/No

Does the child wear glasses? Yes/No

Do you think that glasses help your child to see better? Yes/No

Can your child read?

Describe how your child explores new objects (visually, auditorily, tactile or a combination).

Is your child sensitive to glare?

Communication

Forms of communications that my child uses

- Emotional reaction (facial expression, smile, look, etc.)
- Direct actions (pushing objects, grabbing someone's hand, etc.)
- Natural gestures (waves "Hello" and/or "Goodbye", pointing at objects, etc.)
- Vocalizations and sounds
- Sign language
- Speech
- Augmentative devices (tablets, word cards, PECS, etc.)

The main form of communication that my child uses:

My child's communication skills are better described as:

- He/she shows the behavior (vocalizing, gazing) that I need to interpret, but an unfamiliar person will have difficulties understanding.
- He/she uses natural gestures that most people can understand.
- He/she uses single words, gestures, pictures or symbols to express simple need (for example, show the gesture "more", or says "drink".)
- He/she uses phrases, short sentences with words, gestures or symbols.
- He/she uses speech or sign language, speaks full sentences.

Annex 2

List of topics for the videos

Communication

Film a video of your child communicating with members of the family, friends, classmates using his preferred forms of communication. For example:

Emotional reaction (facial expression, smile, look, etc.)

Direct actions (pushing objects, grabbing someone's hand, etc.)

Natural gestures (waves "Hello" and/or "Goodbye", pointing at objects, etc.)

Vocalizations and sounds

Sign language

Speech

Augmentative devices (tablets, word cards, PECS, etc.)

These can be situations when the child is asking about something, or playing, or having a walk, or studying.

Physical development

Film a video of your child:

Moving (walking by himself/herself, walking with support, with special devices, crawling, going up and down the stairs)

Standing up and sitting down

Picking something up from the floor

Kicking the ball

Throwing large objects (ball, toys, etc.)

Manipulating objects (exploring, pushing, moving, taking and giving, picking and throwing, playing)

Self-help skills

Film a video of your child:

Dressing (by himself/herself, with different level of your support)

Having a meal

Behavior

If you find it possible film your child's problematic behavior such as stereotypic behavior or avoiding certain objects and textures.

Orientation and mobility

Film a video of your child moving in familiar surroundings (home, playground, school).

Academic skills

Film a video of your child:

Having a lesson with his teacher or a family member

Performing academic tasks

**Annex 3
Table of exercises**

Tools	Exercise	Frequency
2-3 pairs of gloves with different texture.	Put the gloves on her hands, let her feel them.	Every day for 3-5 minutes

**Annex 4
Tracker**

June 2020

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Gloves with different textures															
	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30



**KATHELIJN
DONDERS**

ROYAL DUTCH
KENTALIS,
NETHERLANDS

[K.DONDERS@
KENTALIS.NL](mailto:K.DONDERS@KENTALIS.NL)



**SONJA VAN DE
MOLENGRAAF**

CRESAM, FRANCE

[SONJA.
VANDEMOLENGRAAF@
CRESAM.ORG](mailto:SONJA.VANDEMOLENGRAAF@CRESAM.ORG)



International Collaboration on Video Interaction Guidance

We, Kathelijnn Donders, working at Royal Dutch Kentalis in the Netherlands, and Sonja van de Molengraaf, working at Cresam, the national knowledge center for deafblindness in France, would like to share our interesting international collaboration with you.

Sonja:

As Cresam's manager and because of my work experience at Kentalis, I thought it would be interesting for my team to be educated in video interaction guidance.

There are 7 consultants working at Cresam who, among other things, have the task to advise family members and/or professionals who support people with deafblindness. Because of our national function, they often must travel the country. In order to advise, it's important to meet the person with deafblindness in its environment and, if possible, to do hands-on assessment. For this, we've been using video materials, but without a methodical approach and without being trained in analysing videos.

In order to develop and formalize a methodical approach, I started researching how to educate my employees, but I couldn't find a specific course on VIG in France. That's when I decided to contact Kentalis, knowing professionals

work there who are educated in this methodology and who also train other professionals. In developing a learning trajectory, Kentalis helped us to adjust the existing program of approximately 1.5 years to our situation in France.

Unfortunately, due to Covid-19, our learning trajectory has some delay, but I hope that in March 2021 my employees can receive their certificate and we can guide family members and/or professionals in enhancing their competences to support people with deafblindness in an adequate and targeted way.

Kathelijnn:

In March 2019, I received the question if I wanted to give training on VIG to Cresam employees together with Marga Martens. Since I am very enthusiastic about the method, I was excited to teach colleagues in France about the method as well.

Marga and I travelled to Poitiers in October 2019. For 3 days, we

taught about the VIG-method combined with theory on deafblindness, using the 4 books on 'Communication and Congenital deafblindness' and the book 'Communicative Relations'. Theory was combined with practice, such as practical exercises and group assignments.

After the theoretical part, we started practicing with micro analyzing video fragments of persons with congenital deafblindness and their communication partner. Together we've looked at the interaction between both persons and how you can approach this fragment from a VIG-perspective as a coach together with a communication partner, in a methodical and empowering way.

After this session, all participants started working on their case. First, they analyzed video fragments of the person with congenital deafblindness and their communication partner. They then watched this fragment again with the communication partner, which was filmed (a review). I have looked at these reviews together with the participants during the supervision moments by Zoom.

Everyone took their lessons and strengths from that supervision to the next meeting with their communication partners.

The second session in Poitiers took place in February. During this session, we practiced a lot with video fragments everyone made and prepared. Again, everything was based on the theory from the previously mentioned books.

In March 2021, the participants will visit the Netherlands to show how they have continued. Also, a plan will be presented on how Cresam is implementing this method in their organization. After this, they will receive a certificate from Kentalis.

The entire training was given in English, which required effort from both parties, but we managed to find the right approach and knowledge exchange took place. Communication is a difficult subject, because how do you know for sure the other person understood you and you understood them? With enthusiasm and faith in each other, we succeeded!

Connection and Learning in the Time of Covid-19 – A Time to Remember for the Ages



GLORIA RODRÍGUEZ-GIL

DIRECTOR LATIN AMERICA AND THE CARIBBEAN, PERKINS INTERNATIONAL, USA.

GLORIA.RODRIGUEZ@PERKINS.ORG



KARINA MEDINA

ARGENTINA REPRESENTATIVE, PERKINS INTERNATIONAL, ARGENTINA.

KARINA.MEDINA@PERKINS.ORG

Introduction

2020 will be remembered as the time when Covid-19 brought the world to a halt, forcing it to reinvent itself. In education, children and teachers had to talk through technology. Deafblind individuals all over the planet shared stories about their isolation, and we all felt their plight in our own skin. In everything, new perspectives on the familiar helped us find our way through the pandemic.

Perkins International Latin America turned to our strong relationships in Mexico, Brazil and Argentina during this time of

reinvention. Despite the pandemic, our *“Bringing the Education of Children with Visual Impairment and Multiple Disability to Scale in Latin America”* Project continued with the generous support of Lavelle Fund for the Blind. While activities adapted to work online, our goals remained unchanged: 1) support schools to become models in their countries; 2) continue national plans with local strategic groups; and 3) advance evidence-gathering on child-teacher change through research. Here are 4 lessons we learned.

(1) Reinvent Research

In 3 model schools located in Morelos, Mexico; Tocantins, Brazil; and Córdoba, Argentina, research deepens our understanding of how Perkins International Academy training stimulates innovative processes and practices in schools. School teams keep a record of the process, from selecting and initiating a change through its implementation in the school's natural work cycle. Research required adjustments, too. While each country's experience,

actions, and program impacts were different, in all 3, children not attending school changed teacher-pupil-family dynamics, and also impacted research methods. These changes opened up opportunities for new actions under new conditions; Perkins invented new ways to collect evidence and new spaces for reflection with videos, presentations and virtual meetings, creating data we would not have had otherwise.

(2) Collaborating on a Law on Virtual Education

“Argentina includes Argentina” is a national strategic group convened by Perkins representing parents and the education, disability, health, policy, communications, and business sectors. When schools had to adapt to a different dynamic and use new tools to reach all the students, the group decided to collaborate on development of a law on Virtual Education,

introduced in the Santa Fe provincial House of Representatives by local representative, Dr. Claudia Balagué. Conceived to mandate training in the new requirements of virtual education, this law shows the power of collaboration across sectors to ensure that even in a crisis, teachers have the resources they need to help every child learn.



MARTA ELENA RAMÍREZ

MEXICO REPRESENTATIVE, PERKINS INTERNATIONAL, MEXICO.

MARTAELENA.RAMIREZ@PERKINS.ORG

(3) Joint Efforts for Children and Families

Ideas para tu calendario en casa

- Identifica rutinas y eventos principales que ocurren regularmente en el día de tu hij@
- Escoge el tipo de calendario que utilizarás
- Representa cada actividad o evento del día. Esto puede ser con un objeto real, una parte de un objeto o un dibujo
- Recuerda hacer todos los días la rutina haciendo el calendario
- Repasa las actividades del día las cuales pueden ser una oportunidad para conversar con tu hij@

ASOMAS Elaborado por: Natalia Nadal Perkins SCHOOL FOR THE BLIND

GENERANDO MOMENTOS DE CALMA EN CASA

Identifica sus emociones y hazle saber a través de su forma de comunicación la emoción que está sintiendo en ese momento

Genera un espacio de calma en el que pueda estar si lo necesita

Mantén una rutina clara que pueda darle sentido de orden, confianza y sea predecible

De acuerdo a lo que necesite tu hij@ disminuye los estímulos inesperados, sonidos muy fuertes o complejos, luz brillante, ciertos tipos de olores

Toma en cuenta en su rutina diaria las actividades que le gusten a tu hij@ y lo tranquilizan, tales como, recibir un masaje, música, ejercicios físicos, difusor de aromas relajantes

Utiliza palabras positivas cuando logre alguna conducta esperada "lo hiciste muy bien", "estoy orgullos@ de ti", "buen trabajo"



ANA LUCIA RAGO

BRAZIL REPRESENTATIVE, PERKINS INTERNATIONAL, BRAZIL.

ANALUCIA.RAGO@PERKINS.ORG



MARÍA A. VAZQUEZ

RESEARCHER, PERKINS INTERNATIONAL, ARGENTINA.

MARY.VAZQUEZ@PERKINS.ORG

EXCHANGE OF EXPERIENCE

The COVID 19 pandemic brought significant change in activities and information about health and education at home, in schools, and in community programs. In Mexico, Perkins joined with longtime partners ASOMAS IAP school, CEMDYS AC school, and a Mexican psychologist and graduate of the Perkins Educational Leadership Program, Natalia Nadal, to produce and distribute infographics

(4) Never Give Up

Tulio is a 9-year-old boy who lives in Brazil with Cortical Visual Impairment and multiple disabilities. When Brazil became a COVID-19 epicenter, he was in third grade in a regular school in Sao Paulo, and engaged in therapies. Tulio and his school were part of the “model schools” program that Perkins is developing in Brazil, but when Tulio’s family moved away from the city to flee the virus, the school lost track of him, halting his progress. After weeks of searching, Perkins was

Conclusion

COVID-19 has sparked solutions that might have seemed impossible even a few months ago. A sense of solidarity and joint work among organizations is opening new doors. The pause in ‘normal’ life brought reflection, reinvention, and the excitement of learning in new ways. The pandemic also shed light on the inequality in which most children with disabilities and their families live, as well as their lack of access to remote learning. Smart-phones, WhatsApp, and teacher

to help communicate best practices. These resources for professionals and families include experiences of hospitalized deafblind patients and their families during the pandemic. In addition, a series of short videos with audio and text descriptions were produced to show examples of how to help children with MDVI/Db participate in home activities when they cannot learn at school.

able to reconnect the school and family, reuniting Tulio with his teachers remotely. Still, Tulio needed adaptations to complete school activities at home. Perkins provided the guidelines to help his mother facilitate his learning and his comprehension of why he could not go to therapy and school anymore. Today, the family is encouraging Tulio to be more involved in daily activities, turning lost time into a time of learning and growth.

guidance can build bridges, but systemic change is needed to fill this gap.

Perkins International has the duty and opportunity to mobilize, listen, observe and innovate in this time. As schools return to full in-person interaction, our hope is that the world will continue to make new connections and offer more equitable participation for children with MDVI/Db. Much work remains to be done between school and home to make the right to education beyond school walls real, leaving no one behind.

Support to Everyone

To provide developmental conditions to every child. To provide assistance for parents to set out their interaction with the child who has dual sensory impairment. To unite professionals, who work with deafblind children. These three principles were placed in the basis of the project “The Resource Centers” of the Charity Fund “Deafblind Support Foundation “Connection” (hereinafter referred to as The Fund).

Nowadays, in the 15 regions of the Russian Federation, centers providing support for deafblind opened. Those centers are carrying out the work aimed at support of the individual development of a child with bisensory disorders. The assistance for families is provided; the educators in the regions are supported as well. Within the frames of the project, 110 specialists received further professional training in the field of the work with deafblind.

The article presents the experience of one of those centers in Verkhnyaya Pyshma, Sverdlovsk region.



The resource center was officially opened on 12 September 2018 in a school with long traditions of the work with the visually impaired children (S.A.Martirosyan Verkhnyaya Pyshma School). Before the resource center foundation, the school teachers lacked experience in teaching the deafblind. For that reason, the specialists received additional professional training according to different educational programs for the deafblind. That enabled to arrange the assistance for families of the deafblind. The Perkins School for the Blind was Fund's partner.

Currently, the resource center works in the following fields:

Consultative – families have an access to legal, medical and psychological assistance.

Educational – the aim is to expand socialization possibilities of children by means of interaction with other schools and training specialists to work with deafblind children.



**ELENA
VOROSHILOVA**

CANDIDATE OF SCIENCES, HEAD OF PROJECT “DEVELOPMENT OF A NETWORK OF RESOURCE CENTERS AND INTERNATIONAL EDUCATION OF SPECIALISTS”

E.VOROSHILOVA@SO-EDINENIE.ORG



**TATIANA
BESSONOVA**

DEPUTY HEAD OF THE REGIONAL RESOURCE CENTER FOR THE DEVELOPMENT OF THE SUPPORT SYSTEM FOR DEAFBLIND CHILDREN IN THE SVERDLOVSK REGION

EXCHANGE OF EXPERIENCE



Methodological – provides guidelines and support for specialists who work with deaf-blind children.

Scientific-research – realization of research projects related to the deafblind.

Educational – provides training in order to assist social inclusion of children with sensory disorders.

There are two more fields aimed to help the child and the family, namely diagnostics and remedial and developing teaching.





The resource center specialists define their goal as the need to identify children with bisensory disorders in order to arrange further assistance for them and their families. At present,

specialists get information concerning the deaf-blind children from the Fund census base, from regional social organizations, and educational and healthcare institutions. Next, the resource center specialists get into touch with child's family and inform them about the possibility to receive assistance and support. If they agree, both parents and the child are invited for diagnostics. According to the diagnostic findings, the IEP is created. For the families who live far from the resource center, it is possible stay in the school for the period of diagnostics and IEP development.

Despite its short history in Sverdlovsk region, the center has a positive experience of inclusion children into the social and educational environment. Currently, 9 families with deafblind children are permanently supported by the resource center.

And the fact that regional authorities recognize the social importance of the activities is one of our best achievements. It started as a social initiative of the Fund (a support center for the deafblind), then it received the government support of the region, and currently the center activity is being financed by the region funds.



Sparkling Circus Artists at Bartiméus

CINDY NIEKERK

CARE SPECIALIST
DEAFBLINDNESS

[CNIEKERK@
BARTIMEUS.NL](mailto:CNIEKERK@BARTIMEUS.NL)

MIJKJE WORM

PSYCHOLOGIST

[MWORM@
BARTIMEUS.NL](mailto:MWORM@BARTIMEUS.NL)

BARTIMÉUS
EXPERTISE CENTRE
DEAFBLINDNESS,
THE NETHERLANDS

A few years ago, I was touched by a theatre performance by people with deafblindness. Each individual had a role according to his or her abilities. I imagined what this kind of expressive activities could offer the clients of Bartiméus. With the financial support of the Bartiméus Foundation, we collaborated with circus theatre company Stoffel. They had prior experience with people with disabilities and knew how to stimulate them through circus activities.



Fig. 1. Tightrope © Rob Kuiper Circustheater Stoffel

Discovering

Walking on a ball, floating through the air, spinning rings together: fourteen clients with congenital deafblindness took a series of 12 weekly circus lessons. The hall was buzzing as the clients juggled, balanced and showed their talents. During the lessons, the clients were artists... so that's how they were called. Their proud smiles were visible while discovering the circus activities!



Fig. 2. Balancing © Rob Kuiper Circustheater Stoffel

Aims

With the circus project, we had three main aims:

1) To offer people with congenital deafblindness more creative activities.

Persons with congenital deafblindness have few opportunities to experience new exciting events. Often, it is a challenge for them to express their feelings and creativity. Being involved in circus activities would offer them new experiences in a joyful manner. It could bring personal growth and solidarity for all participants.

Of course, the care professionals also participated. During the classes, the possibilities and interests were examined for each artist. Some artists were somewhat frightened, but together with a trusted care professional and the circus teacher they overcame their fear. The shared experience of circus activities deepened the relationship between the artists and the care professionals.



Fig. 3. Sitting on a circusball © Cindy Niekerk

2) The persons with deafblindness and their care professionals can share their experiences and emotions about the activities within their interaction and communication.

If someone experiences new and exciting things, they feel the need to share their stories with others. The idea was that attending the circus would bring new opportunities for communication.

3) Very important: having a lot of FUN together.

EXCHANGE OF EXPERIENCE

Juggling Cloth as Referential Object

Having a fixed structure, the lessons were predictable and recognizable. For example, there was always circus music playing upon arrival, everyone was greeted individually by the circus teachers with the aid of a juggling cloth: the referential object of the circus.

A lesson consisted of fixed elements, to which we added something each time: balancing, learning to work together with others for an act. A bigger circus activity in the lessons was balancing on the big ball, walking on the tightrope or the trapeze.

Before each activity we asked ourselves how we could communicate with each artist about what was going to happen and which means of communication was needed: a gesture, a brief demonstration, an icon, or simply go through the experience together. In

that case, we payed attention to the body language to see if it was comprehensible and not too exciting.

After the bigger circus activity, which often took much effort for all involved, it was time to relax and process the events. Artists who wished to continue could practice with other circus objects, such as the maces, juggling balls and spinning plates.

When the lesson was over, the circus teacher showed the juggling cloth again and said goodbye to the artists. Some of the smaller circus objects, such as the juggling balls and flower sticks, could be taken home to practice in between the lessons. This way, the circus project also brought new activities in the daily lives of the clients, and they could show their progress during the lessons.



Fig. 4. Standing on a circus ball © Cindy Niekerk



Fig. 5. Human pyramid © Rob Kuiper Circustheater Stoffel

Pushing Boundaries

The results of the circus lessons were presented in an open lesson for in total 50 relatives and interested parties. The audience was welcomed by the circus director and enjoyed the performances of the circus artists. The artists built a human pyramid and walked on a big ball. Thereafter, the audience was invited to experience themselves what it was like to walk on a tightrope. If

they needed support, they were accompanied by the artists, which gave the artists a new role. Everyone was enthusiastic. Such a new memorable experience together, brings lots of beautiful new things. This project has been a great success and we are now investigating how we can continue this for much more clients of Bartiméus.

DBI Australia 2019

Maybe there is a circus school in your neighborhood. But what if you don't have a circus nearby? Is it still possible to do circus activities? Yes, was the answer at the DBI conference in Australia, August 2019? During my workshop about this project I brought some simple attributes, such as juggling rings,

spinning plates and flower sticks. Attendees of the workshop who had visual and hearing disabilities loved exploring and trying out these attributes. And the good thing is: they are available on internet, often inexpensive and have all the options to have a good time together!



Fig. 6. Spinning rings © Rob Kuiper Circustheater Stoffel

EXCHANGE OF EXPERIENCE



Fig. 7. Spinning plate © Rob Kuiper Circustheater Stoffel



Fig. 8. Flower sticks © Cindy Niekerk

Regional Information Accessible on Live TV Programs for Deafblind People

Abstract

The deafblind community has social barriers of different nature; one of these barriers is the accessibility to information. A widely used medium today to communicate information and even entertainment is television; access to the content transmitted by television is a topic that has been worked on in our research group for some time. This article presents an extension of our previous work, which allows deafblind people to access even live television broadcast programming,

since we have developed a module that allows, through the presence of audio, to generate captions automatically and in real time, which is also capable of learning from previous broadcasts, which allows us to constantly improve the quality of captions. The aim of making these improvements to the system is to allow the deafblind community to have access to the same television content as any other non-disabled person, and to obtain this access directly and free of charge.

Acknowledgments

We would like to thank all the people from the Broadcasting Department and the Innovation Department of RTVE and the deafblind people who are testing

the system, for their constant support to achieve the goal that all people have access to the information regardless of their circumstances.

Introduction

In a review of the prevalence of deafblindness, which included the largest number of studies (compared to other reviews conducted so far), and 22 countries to be analyzed, it was found that about 0.2 to 2% of the world population has some level of deafblindness, being more likely in older people (World

Federation of the Deafblind, 2018). On the other hand, some studies indicate that deafblind people are the most vulnerable in society, and this vulnerability increases with age (Simcock, 2017; Peter Simcock & Wittich, 2019). This vulnerability, and even isolation, is often associated with the differences of

PERE VILA FUMAS

PhD. GRUPO RADIOTELEVISIÓN ESPAÑOLA, (PLANNING AND TECHNOLOGICAL INNOVATION DEPARTMENT), SPAIN
PEREVILA@RTVE.ES

FRANCISCO ARMERO REAL

GRUPO RADIOTELEVISIÓN ESPAÑOLA, (BROADCASTING AND ACCESSIBILITY DEPARTMENT), SPAIN
FRANCISCO.ARMERO@RTVE.ES

FRANCISCO TRIGUEROS MOLINA

SPANISH FEDERATION OF ASSOCIATIONS OF DEAFBLIND PEOPLE, (MADRID), SPAIN
PRESIDENCIA@FASOCIDE.ORG

ANGEL GARCÍA-CRESPO

PhD. UNIVERSIDAD CARLOS III DE MADRID, (COMPUTER SCIENCE DEPARTMENT), LEGANES, (MADRID), SPAIN
ANGEL.GARCIA@UC3M.ES

ROXANA RODRIGUEZ-GONCALVES

MSc. UNIVERSIDAD CARLOS III DE MADRID, (COMPUTER SCIENCE DEPARTMENT), LEGANES, (MADRID), SPAIN
ROXRODRI@INF.UC3M.ES

ADRIAN RUIZ-ARROYO

MSc. UNIVERSIDAD CARLOS III DE MADRID, (COMPUTER SCIENCE DEPARTMENT), LEGANES, (MADRID), SPAIN
ADRUIZA@INST.UC3M.ES

deafblind people, rather than with attitudinal barriers and access to infrastructure and the lack of knowledge of others about communicating with them (Hersh, 2013). Deafblind people often have social barriers including communication, mobility, access to

information and the general development (FASOCIDE, n.d.; Hersh, 2013). Our research focuses on reducing those barriers or limitations that deafblind people must access information, specifically to information transmitted by television.

Captions in Television Programming

Closed captions have two formats; these can be pre-recorded (offline) or live (real time). Most captions on television programming are pre-recorded offline. For the captions to appear on your television screen at the appropriate time, the captions are integrated into the television

signal and become visible when a special decoder integrated directly into the television is activated. While most new programs and movies have captions, some live programs, as well as some older programs created before the regulation, may not have this option.

Related Work

Previous research has presented the same aim as us, however, the technology they developed is currently obsolete, since, for various reasons, they did not continue with the study and therefore did not update the technology used. Some examples of these are the TeleCaption Braille System (Biederman-Anderson, 1989) and the Closed Caption/Braille Computer System (CCBCS) (AbleData, 2007). These technologies and others are detailed in the research carried out by García-Crespo (2018). On the other hand, large companies like Apple have also contributed to accessibility for deafblind people, since VoiceOver users can access closed captions audibly or through the braille display (Closing The Gap Logo, 2018). Similarly, users with Apple TV can access this information (Apple, n.d.). However, if captions are not available on the programming (e.g., some live broadcast programming), these technologies will not allow the deafblind to access the information transmitted by the television. Several live broadcasts (e.g., some news programs) have captions, as they have a pre-script that broadcasters must follow, however, the speaker may express the same idea in another way, or in the worst case, some of the information may be replaced or removed at the last minute (due to any circumstance), which would create an inconsistency between what the speaker says and the captions generated.

This research is based on the GoAll mobile application (García-Crespo, Montes-Chunga, Matheus-Chacin, & Garcia-Encabo, 2018). In our previous research, a system was developed that allowed the translation of the captions of television programming into braille, in order to transmit them to a braille screen so that the deafblind person could read them. In that study we obtained the subtitles through the information transmission channels of the Spanish digital terrestrial television (DTT).

In a previous study similar work was done as described above, which focused on using the GoAll system for the deafblind community in the United States, creating GoCC4All. In that study the system obtained captions through cable television. The main difference between the two studies was the way the captions were obtained and the country in which the system could be used (considering the limitation in obtaining the captions) (Garcia Crespo, Rodriguez, Diaz, & Collazos, 2020).

The aim of this study is to extend the system developed previously, so that the system can generate captions automatically, eliminating the dependency that the system currently has on the arrangement of captions. Obtaining a system that provides direct, free and equal access to all content broadcast on television to deafblind people. Currently the new version of the GoAll application, which includes the automatic captioning module, is under study in a pilot test.

Real-Time Captioning

For live broadcasts such as special events, news programs and sports events, captions are created and presented in a different way. Currently there are three methods used by television stations; in the first, the captions, instead of being pre-recorded, are written by a stenographer who is listening to the live broadcast in real time and writes the words in a special computer program that adds the captions to the television signal. This method generates a delay in the presentation of the captions; the quality of the content and the accuracy of the captions will depend on the stenographer's spelling skills and typing speed (Block & Okrand, 1983).

The second method is used in live programs that present a script for the speakers, in this case pre-recorded captions are used and one person is in charge of synchronizing these captions taking into account the speed with which people speak in the event, this method is simpler than the previous one and requires less experience from the employee who performs the synchronization task. However, considering that this is a live television program, it is likely that the script will not be followed perfectly, it may even eliminate part of the script or be changed completely by actions that occur in the middle of the program, and therefore, the quality of content of the captions can be seriously affected.

The third method used is through a respeaker, this method requires a person to repeat what she or he is hearing live, while using all relevant punctuation marks when speaking. This voice is then translated into text through a speech to text software (voice recognition

software) and presented on television (Brousseau et al., 2003; Pražák, Loose, Trmal, Psutka, & Psutka, 2012; Romero-Fresco, 2012). This method often presents problems in the quality of the content of the captions, since many times respeakers paraphrase what they hear, since they have to do the whole process as fast as possible (using punctuation marks while performing the dictation and listening to the original soundtrack, all at the same time).

All these methods can present two types of errors, one from the computer area (software and hardware) and the other caused by the personnel that performs the task of adapting the information to present it as captions on the television. Our study is focused on automating the process currently performed by the staff that adapts the information, since we use the original audio to generate the captions.

There are studies that allow to automate the synchronization of the captions (previously written) with the audio of the program that is transmitted live. One of the works focused on news programs, even allows to move part of the script if in the live programming do not respect the order that was presented in the script (Ortega, Garcia, Miguel, & Lleida, 2009), however, as mentioned above, this is only valid if it is a programming with previous script, which is not always possible. This can be difficult in a live interview or in live event narrations, besides this, in news programs the speakers can paraphrase part of the news and this would not be correctly written in the caption.

The Technology

In previous work by our research group, we have developed a system that allows deaf-blind people to access information provided by television. This system is based on the European standard of digital terrestrial television transmission (DVB-T), and it is constituted with a server that transmits in real time the captions of all the programs of the different channels of the digital terrestrial television; and an application called GoAll

(compatible with iOS and Android operational systems) that connects to that server asking for the captions of a specific channel. In addition, this application translates the captions of the programming into braille language and sends it to a braille screen by Bluetooth so that deafblind people can read them and understand the programming transmitted by the television (García-Crespo et al., 2018). However, there are television programs that

do not have captions, there are also television programs that have captions but these are out of sync with the audio or do not transmit correct transcript of what the speaker is communicating, this usually happens in live broadcast programming, which, even though they may have a script, speakers can paraphrase the content of the script, or the speaker's dialogue can be changed by events occurring in the live programming.

The present study aims to change the previous system. A system module has been developed that is capable of automatically generating captions of any transmission in real time; this module is cloud based which allows an increase in the quality of closed captions

through automatic learning techniques. The system only requires access to the audio of the programming. The system architecture has a parameterizable and scalable scheme, which allows simultaneous transmission without affecting the quality or speed of the captions of each broadcast. The captioning process feeds back to the recognizer, so the more captions the system generates, the more accurate it will be in future broadcasts. The audio from the programming is sent to the cloud servers which transcribe it into text. These captions are available not only for the GoAll application, but also for television programming, so that deaf users can watch them on television as well. Figure 1 shows an overview of the current GoAll system.

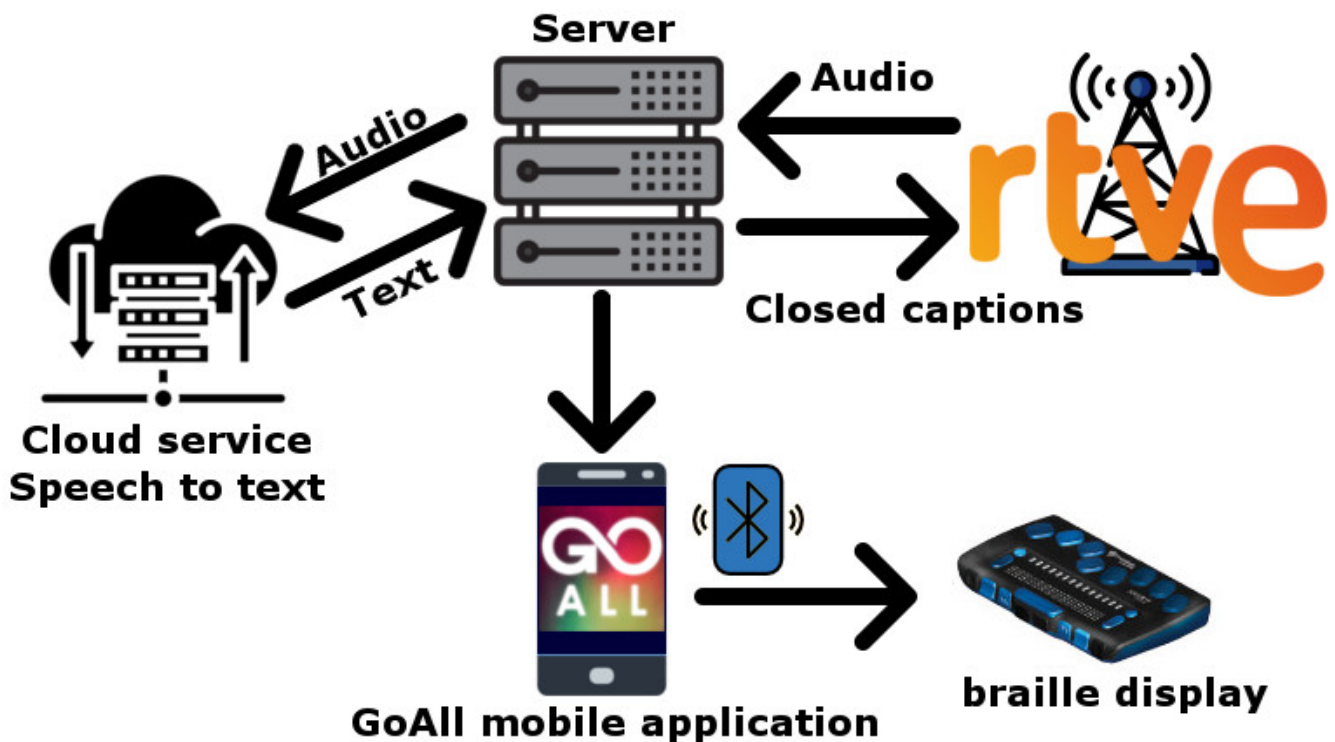


Fig. 1. General structure of the GoAll system

GoAll at Present

Currently, a research group from the University Carlos III of Madrid (UC3M) in collaboration with Radio Televisión Española (RTVE) is conducting a study of the GoAll application, which includes the automatic captions module of the programming. Before we started with this project, our automatic captioning system was responsible for generating the automatic captions of some

RTVE's territorial news programs. The territorial news programs are live productions of the news from each of the regions of the Spanish territory. Our project began by generating the automatic captioning of a first territorial news program in September 2019, to date our system is generating the captions of the news program from 10 different regions of Spain.

Our main motivation to carry out this study came from our previous project aimed at the deafblind community, in which we understood that deafblind people like the rest of society are interested in local news and currently do not have access to this information in real time (García-Crespo et al., 2018). Considering the work, we already had done with regard to automatic captioning, we decided to start a pilot test in collaboration with RTVE, in which three of the regions we currently subtitle (Madrid, Castilla-La Mancha and Andalusia) were chosen for the test.

The pilot test was designed to be carried out in six months and is currently in its third month. In each territorial region there are deafblind people who are using the GoAll application to watch the two daily territorial news programs, in order to write and transmit us a report of their personal experience using the application. This is being done in collaboration with the Spanish Federation of Associations of Deafblind People (FASOCIDE). In the first report that they sent us, we observed very positive comments regarding the usability and the experience that the users had when using the application, however,

they have also indicated some recommendations to improve the functionality of the application. Among the recommendations described in the report, they indicate that some toponyms (proper name of a place) appear incorrectly in the captions. To solve this, we have decided to introduce the toponyms in the captioning system through a phonetic analysis of the speech, in order to make them appear correctly. Another recommendation they indicate in the report is that when using the application, they could not know who was speaking, since the application does not present a functionality to identify the speaker. To solve this, a module has been developed that allows the identification of the main speaker of the news program. During the next three months of testing, users will test these two new functionalities of the application so that we can improve user satisfaction.

Figure 2 shows the GoAll application with the transmission of the three territorial news programs in Spain with which the pilot test is carried out. On the other hand, figure 3 shows a user using GoAll to access the information of the live news broadcast of Radio Televisión Española, in the pilot test of the application.



Fig. 2. GoAll application



Fig. 3 Deafblind user using the GoAll application in the pilot test.

Conclusions

In conclusion, deafblind people have sensory challenges that put them at a disadvantage with respect to information accessibility. Therefore, it is necessary to continue to carry out studies and to update the existing developments, in order to provide them with an assistance tool that allows them to access this information directly and free of charge. On the other hand, this developed technology must be scalable for future updates, to prevent the system from becoming obsolete in the future (which has happened with previous developments).

Currently, besides GoAll and Go4CCall (two systems that share the core of the technology), there is no other study or technological development that allows deafblind people to have access to live television broadcasts. With the new module for generating captions developed in this study, we have expanded the functionalities of the two previous systems, eliminating the dependencies that both had with respect to obtaining the captions.

References

AbleData. (2007). Braille Telecaption System. Retrieved August 5, 2020, from <https://abledata.acl.gov/product/braille-telecaption-system>

Apple. (n.d.). Accessibility. Retrieved August 5, 2020, from <https://www.apple.com/accessibility/tv/hearing/>

Biederman-Anderson, L. (1989). Braille Telecaptioning: Making Real-Time Television Accessible to Deaf-Blind Consumers. *Journal of Visual Impairment and Blindness*, 83(3), 164–165. <https://doi.org/10.1177/0145482X8908300311>

- Block, M. H., & Okrand, M. (1983). Real-Time Closed-Captioned Television as an Educational Tool. *American Annals of the Deaf*, 128(5), 636–641. Retrieved from <https://www.muse.jhu.edu/article/506470>
- Brousseau, J., Beaumont, J., Boulianne, G., Cardinal, P., Chapdelaine, C., Comeau, M., ... Ouellet, P. (2003). Automated closed-captioning of live TV broadcast news in French. In INTERSPEECH.
- Closing The Gap Logo. (2018). Iphone – As accessible as it is personal. Retrieved August 5, 2020, from <https://www.closingthegap.com/iphone-as-accessible-as-it-is-personal/>
- FASOCIDE. (n.d.). Deafblindness – Definition. Retrieved July 30, 2020, from <http://www.fasocide.org/en/deafblind-community/deafblindness-definition/>
- García-Crespo, Á., Montes-Chunga, M., Matheus-Chacin, C. A., & Garcia-Encabo, I. (2018). Increasing the autonomy of deafblind individuals through direct access to content broadcasted on digital terrestrial television. *Assistive Technology*, 1–9. <https://doi.org/https://doi.org/10.1080/10400435.2018.1543219>
- Garcia Crespo, A., Rodriguez, J., Diaz, M. V., & Collazos, O. (2020). TV Caption Access Technology for Individuals Who Are Deaf-Blind. *DBI Review*, (63), 75-85.
- Hersh, M. (2013). Deafblind People, Communication, Independence, and Isolation. *The Journal of Deaf Studies and Deaf Education*, 18(4), 446–463. <https://doi.org/10.1093/deafed/ent022>
- Ortega, A., Garcia, J., Miguel, A., & Lleida, E. (2009). Real-time live broadcast news subtitling system for Spanish. Proceedings of the Annual Conference of the International Speech Communication Association, INTERSPEECH.
- Pražák, A., Loose, Z., Trmal, J., Psutka, J., & Psutka, J. (2012). Captioning of Live TV Programs through Speech Recognition and Re-speaking. https://doi.org/10.1007/978-3-642-32790-2_62
- Romero-Fresco, P. (2012). Quality in Live Subtitling: The Reception of Respoken Subtitles in the UK (pp. 111–133). https://doi.org/10.1163/9789401207812_008
- Simcock, P. (2017). One of society's most vulnerable groups? A systematically conducted literature review exploring the vulnerability of deafblind people. *Health Soc Care Community*, 25(3), 813–839. <https://doi.org/10.1111/hsc.12317>
- Simcock, Peter, & Wittich, W. (2019). Are older deafblind people being left behind? A narrative review of literature on deafblindness through the lens of the United Nations Principles for Older People. *Journal of Social Welfare and Family Law*, 41(3), 339–357. <https://doi.org/10.1080/09649069.2019.1627088>
- World Federation of the Deafblind. (2018). At risk of exclusion from CRPD and SDGs implementation: Inequality and persons with deafblindness. Oslo, Norway. Retrieved from https://www.internationaldisabilityalliance.org/sites/default/files/wfdb_complete_initial_global_report_september_2018.pdf

Independent Dialogue between People with Hearing Impairment, Including Deafblind and People without Health Limitations. *Charly* Makes It a Reality

ALEKSANDER TOROPTSEV

PROJECT MANAGER
OF POLYGON

POLYGON@SO-EDINENIE.ORG

OLGA CHEBUNINA

DEVELOPMENT
DIRECTOR OF
SENSOR-TECH
LABORATORY

OCHEBUNINA@SENSOR-TECH.RU

DANIIL KUZNETSOV

PROJECT MANAGER
OF SENSOR-TECH
LABORATORY

KUZNETSOV@SENSOR-TECH.RU

Can people with hearing impairments, including the deaf-blind, communicate independently with people without hearing impairments without the assistance of special interpreters? The specialists of *Sensor-Tech* Laboratory say “YES”.

As we know, people with simultaneous hearing and visual impairments are seriously limited in communication methods. The most common method of successful communication is to engage an interpreter who interprets speech of a speaking person into sign language and transmits information to a deafblind person using “palm-to-palm” method. Another popular method for communication between a deafblind person and a person without health limitations is to communicate through a smartphone with a connected Braille display. However, this

method is more suitable for remote communication, for example, via messengers, social networks or e-mail. It is also worth noting a number of disadvantages of this method, which can include the absence of a smartphone itself, or a Braille display as well as not having an account in social networks. It is particularly relevant to people of the older generation.

A few years ago, a specialist of *Sensor-Tech* Laboratory developed Speech recognition device *Charly* using advanced technologies. *Charly* is a small device with

built-in microphones which is designed for recognizing speech and translating it into text in a real-time mode. The device can be connected to a monitor, a TV or a Braille display. By means of 4 built-in microphones, the device recognizes speech of the speaking person and displays it on a monitor, a TV, a tablet, which is relevant to interaction with people with hearing impairments. Or else the device displays text on a Braille display, which is applicable for interaction with people with simultaneous hearing and visual impairments. It should be noted that it takes *Charly* only a fraction of a second to recognize speech and display text on the necessary device (a display, a monitor, a tablet, a Braille display), which allows to maintain real-time communication.

Similarly, text gets transmitted to a Braille display and thus a deafblind person can read what has been said. Here is how it works: speech of the speaking person is caught by microphones, gets processed by a program and converted into text in real time, i.e. immediately. And this text is displayed on a Braille display. Also, there is an option to answer with a Braille display, or with a usual keyboard connected through USB. To do so, the user has to push one button on a Braille display and then enter letters in Braille, as in ordinary communication.

Not only can the user read information on a Braille display received through *Charly*, but also answer using a Braille display. Also, there is an option to connect an ordinary keyboard to the device, which is relevant to interaction with deaf people.

Let us examine in detail the description of using *Charly* with a Braille display. As mentioned above, the combination “*Charly* – a Braille display” allows to read the information transmitted by the interlocutor as well as answer using the Braille display. A Braille display is connected to *Charly* through a USB port. Speech of the interlocutor, for example, a bank operator or a specialist in a social service, where a deafblind visitor has addressed for a service, is recognized by microphones embedded in *Charly*, then gets processed by the software installed in *Charly*, and is displayed in a few seconds on a

Braille display line. Further, the deafblind visitor, if he or she knows Braille, reads the text that the operator/specialist pronounced, on the Braille display. To answer the interlocutor, i.e. the bank operator or a specialist in a social service, as in our example, the deafblind visitor types Braille letters as in ordinary communication, only first pushing one button on the Braille display, which enables answering the interlocutor. As the text has been typed, it is displayed, also in a few seconds, on the screen (a monitor, a tablet, a TV) which is connected to *Charly*, in a language understandable for the interlocutor (the operator/specialist), for example, in Russian or in English. Thus the dialogue between the deafblind and a person without visual and hearing impairment is conducted.

By far, *Charly* has proved to be a successful assistant for communication with people with hearing impairments in social, medical, educational, financial and rehabilitation organizations – where the staff uses *Charly* for communicating with people of this group when providing services.

For instance, in the offices of social and financial organizations one working place is specially equipped with *Charly* and the necessary equipment, and one employee serves specifically people with hearing impairments. This significantly simplifies interaction of the organization's employees, reduces both the time of customer service and optimizes costs of the office at large, and increases quality of service and the loyalty of the visitors of this group. This audience increases compared to the period when the organization did not use *Charly* in its work. The visitors with hearing impairments themselves note, “We come particularly to you because they understand us here”, “They understand us and can provide a necessary service quickly and qualitatively”. That is the kind of phrases that we hear from visitors of our clients, for example, from the Moscow employment center where *Charly* is actively used in the division for the employment of persons with disabilities and from the clients of the multifunctional service center (MFSC) where they provide public services to the population. It should be also noted that *Charly* has a function to record and store information,

i.e. in this case it is possible to record and store the conversation with visitors, which is a useful function for public agencies and institutions, in particular for social services.

As far as medical and rehabilitation centers are concerned, the device is widely used at the registries of such institutions where visitors, including ones with hearing impairments, come. Also, separate rooms are equipped with the device where specialists receive visitors – medical workers receive patients for the purpose of efficient interaction with the patients of the organization. As employees of these organizations note, with the installation of *Charly*, there has increased a flow of visitors with hearing impairments, the reception time of such patients has reduced by half, on average. Also, the quality of services provided has increased due to correct understanding of all problems of the patients. And it is significantly easier and more comfortable for the patients with hearing impairments themselves to communicate not like before – through signs and “pieces of paper” that they used to write their problems on, but through a modern device *Charly*.

We would also like to pay attention of our readers that *Charly* can be applied and is already being successfully used in educational organizations where with the help of *Charly* they conduct lectures and practical classes with students with hearing impairments and the deaf-blind as well as student meetings. Functionally, the interaction is carried out in the same way as described above. *Charly* allows for students to perceive information at their own rhythm (pace). And the major thing is that *Charly* allows to receive information of a better quality. And, on the whole, it should be noted that a greater number of students with hearing impairments, including the deaf-blind, can receive an education, and their choice options are increasing as more educational organizations apply *Charly* in their work.

Besides the aforementioned organizations, it is worth paying attention to *Charly* being

used at mass events, for example, forums, conferences, symposiums, etc., with the participation of people with hearing impairments, including the deaf-blind, where it is quite difficult to communicate with all participants. And the use of *Charly* considerably simplifies communication task. It only requires a participant to have a smartphone and Internet connection. This is how it looks: a participant of the event connects a smartphone to *Charly* after first downloading *Charly* mobile application in Play Market for Android, and in AppStore for iOS. After that, the participant would have access to the event chat, where he or she would see the whole dialogue between other participants, including speakers and hosts and would be able to him- or herself join the conversation, typing a text into the chat. There is a function to set the font, color characteristics in the chat, the user gets access to various settings. Thus, *Charly* recognizes speech of the speakers and the participants and displays it as text in the mobile app, and vice versa, what a participant types into the chat is displayed through *Charly* on the necessary screen (a TV monitor, a tablet, a display). We would like to emphasize once again that this functionality allows participants with hearing impairments, including the deaf-blind, simultaneously communicate with one another as well as with the speakers of the event, which would be impossible otherwise.

To conclude this paper, we would like to emphasize again that due to the Speech recognition device *Charly* developed by the specialists of *Sensor-Tech* Laboratory, what seemed impossible became a reality. People with hearing impairments, including the deaf-blind, can communicate freely with people without sensory limitations. The mentioned in the article functions and characteristics of the device as well as the spheres of its application once again confirm the status of *Sensor-Tech* Laboratory as an innovator in the field of technologies and their application for people with hearing impairments, including the deafblind.

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.