

#63 | April 2020

E-version #1

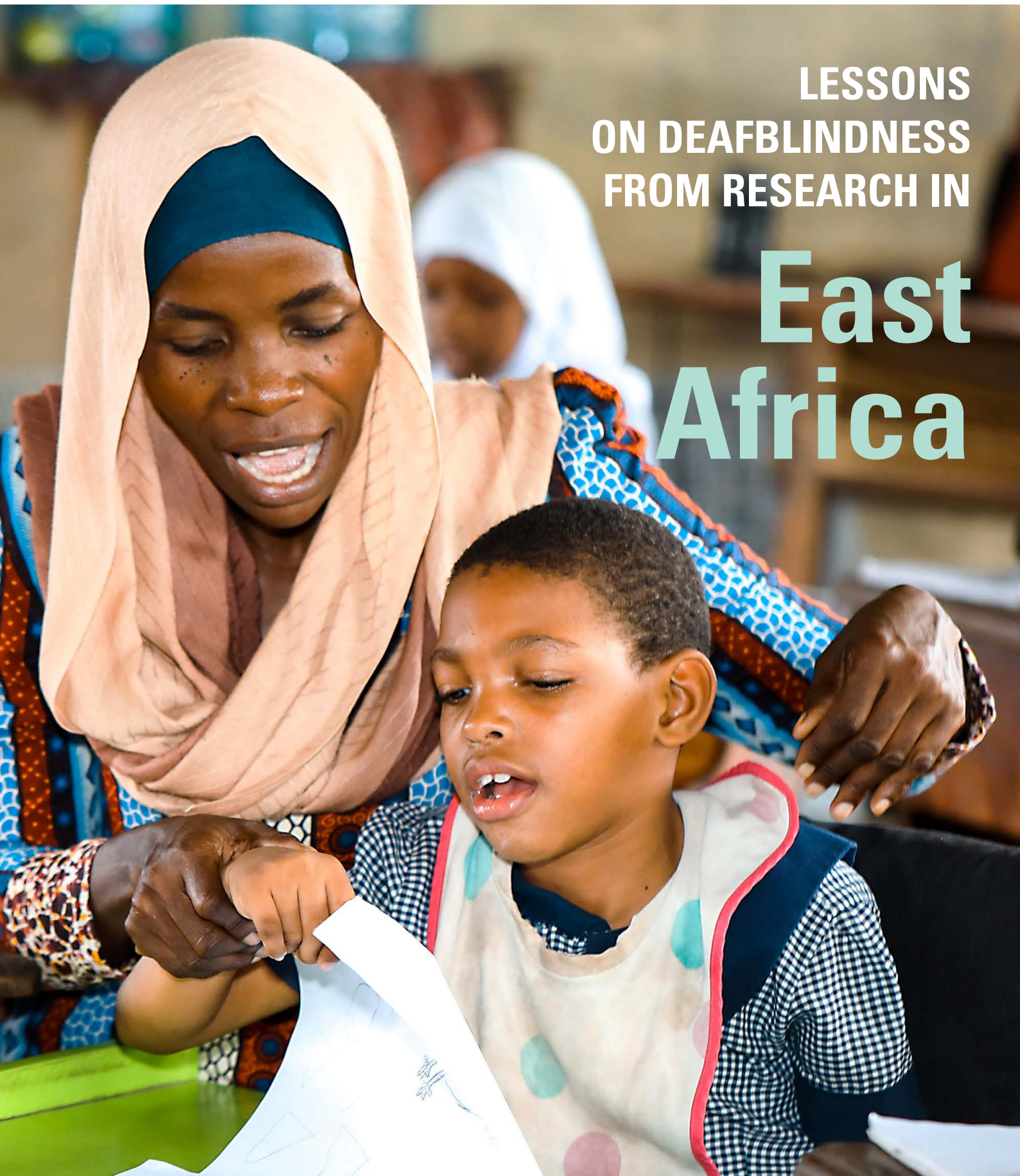
# Dbi REVIEW

THE MAGAZINE  
OF DEAFBLIND  
INTERNATIONAL



LESSONS  
ON DEAFBLINDNESS  
FROM RESEARCH IN

## East Africa





# 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



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# Kindness and solidarity



In this first redesigned DBI Review I wanted to start with thanking all of the people who worked hard to get this online. I'm glad we are able to share our experiences, findings and stories again in our magazine. Since last summer we've had a new Board and ManCom helping to make steps forward for DBI. We have already had a number of successful meetings where we, among other things, have formed special working groups, like the Communication Committee. We see ourselves more and more as the point of connection in deafblindness worldwide.

However, we are facing challenging and difficult times because of the COVID-19 situation. I am in contact with a lot of professionals in the field, and all are trying to do whatever is possible. As we all know, people with disabilities and

the services they use are experiencing really difficult times. Now, more than ever, is a time for us to find each other and stand together, a time of solidarity but also a time of kindness.

Kindness comes in many forms, and taking the time to communicate is indeed an act of kindness. We equally know how important communication is for people with deafblindness and how they will need patience and reassurance in such an unsettling period.

It is important that we stand together and support each other in these times, and it makes our DBI Review all the more important. I am therefore pleased to present our new issue. I hope you enjoy the articles and stories of our colleagues, keep in contact and stay safe.

**FRANK KAT**

PRESIDENT OF DBI

# Dbl network coordinator reports



**TREES VAN NUNEN**

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Last year, in my new role as network coordinator, I analyzed the functioning of the networks and discussed my findings during the meetings of the Dbl Management Committee (ManCom), the Board and the Communication Committee (ComCom).

Fortunately, more than half of the networks are functioning very well! Thanks to Graciela Ferioli who played such an active role in stimulating the network leaders to make a video clip to promote their network and invite people to join.

We learned from the surveys among the members of Dbl that people think the networks are very important. The functioning of the networks cannot be viewed separately from communication and the use of social media. Now ComCom is working hard to revise the different sites of the networks, also to keep the information up to date. We always involve the network leaders in this.

During the Dbl conference in Australia last August, we agreed with the network leaders present that we would meet regularly. This has already resulted in two Zoom meetings. The purpose of these meetings is not only to discuss the needs of the network leaders and

their network, but also to inform each other about all kinds of matters. We also try to support networks that may be less active for whatever reason. Do not forget that many network leaders also have a busy job as a professional. In order to spread the responsibilities, we asked the network leaders to involve a second person from their network. Other good news is the fact that the budget for the networks has increased.

Looking back at the past period, I am very happy with all developments concerning the networks. I hope that everyone will enjoy reading the articles about activities organized or still being organized by the various networks. In addition, I call on everyone to join one or more networks of special interest. Finally, I would like to say a big thank you to all the network leaders and others who work so hard to keep their network active and to keep their members informed about new developments and activities.

# Usher Network reports

Eight very fast months have passed us by since the fabulous Dbl Usher Network Pre-conference. Although the world has changed massively and in so many ways, what remains very strongly are the memories and experiences that come from the networking and positive interactions with friends and colleagues from all around the world.

During the pre-conference, we all learnt a huge amount of information from the speakers. The very important theme of mental health and wellbeing was featured prominently and was taken on board by all the attendees. This resulted in an update to the Dbl Usher Network webpage, which can be found at: <http://usher.deafblindinternational.org/pre-con-aus2019/>.

I have to thank all the committee members for their fantastic work before, during and after the event. We have had all the reflection sheets back and, having considered them, we see that the event is very important to everyone and much more work is needed now

and into the future. It is important we continue to work and pull together to make the world a better place for those people who so often miss out on opportunities. This will spur us on to continue our efforts.

The Usher Network is ever changing and evolving. We are always keen to hear about news, stories, views and blogs by anyone connected to us from anywhere in the world. We are always open to new committee members and more contributions from all people who are involved with Usher syndrome. Please do not hesitate to get in touch: [emma.boswell@sense.org.uk](mailto:emma.boswell@sense.org.uk).

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# Preconference Communication Network.

## 17<sup>th</sup> Deafblind International World Conference “Sharing the knowledge to ACT. Accessibility. Communication. Technology. Now is your time to ACT!”

Gold Coast, Australia. August 12, 2019

REVIEWED BY

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Ahead of the 17th Deafblind International World Conference in the Gold Coast, Australia, the Communication Network hosted a pre-conference on August 12, 2019. Presenters from five countries were organized by Marleen Janssen to share their experience of video analysis and communication.

The day started with presentations from the Japanese delegation featuring fascinating videos of co-created communication between children with congenital deafblindness and the presenters themselves, which included Hiroyuki Sugai (Miyagi University of Education), Yasukazu Nakamura (Gunma University), Shinichi Okazawa (Utsunomiya University), and Yoshimi Tsuchiya (Joetsu University of Education). One memorable video of a child exploring inside his communication

partner's mouth was a reminder that following the initiatives of an individual with deafblindness can result in unconventional but meaningful interactions. Next, three presenters from the Dutch delegation shared their Ph.D. studies from the University of Groningen. Kirsten Wolthuis, Marianne Rorije, and Mijkje Worm educated us on a range of theoretical frameworks and processes they used in analyzing communication and language; it was affirming to see the role of videos in each of their studies.

The third delegation included presenters from Sweden, starting with Maria Creutz, who talked about the Nordic Welfare Centre. Ingrid Axelhed, Caroline Lindstrom and Kristina Strom then presented on language in the tactile modality. For anyone in the role of a communication partner or intervenor, it was inspiring to see how flexible the partners were with regard to the deafblind person's positioning in activities like woodwork-ing. Finally, there were two presentations from the Alumni delegation of the Master's in Communication and Deafblindness from the University of Groningen. Kirsten Costain from Norway showed a video of an initial in-teraction with a young child and presented on the usefulness of video in assessment and consultation. Lastly, Rachel Kavanagh shared her thesis study, which explored the concept of voice for a child with congenital deafblindness using video analysis.

The Dbl Communication Network pre-con-ference provided an opportunity to discuss various approaches which support commu-nication and language development within the context of video analysis. Every pres-entation was an opportunity to engage in ro-bust discussion between the presenters and attendees, highlighting the variety of per-spectives and experience in the room. The heterogeneity of the deafblind population can create challenges for discussion; how-ever, using videos as a focal point allowed for a depth of interaction that can other-wise be difficult to achieve. Additionally, the frameworks provided by the various theo-ries bridged differences in the observations and subsequent discussions. Regardless of people's experience with this kind of group analysis, the analytical lenses, knowledge and reflections shared throughout the day were truly informative and inspiring.

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# Communication Network reports

We have expanded the Communication Network team with Meredith Prain from Australia and Helle Buelund from Denmark. We will work on a members list and a website page, which will be linked to the page of Dbl, and we will keep you informed about our past, current and future activities.

## **DbI Review book on communication: overview of 40 years**

Making a book of all interesting articles about communication published in the DbI Review over the last forty years.

## **Newsletter**

Meredith will set up a newsletter with relevant information for the mem-bers of the communication network, which will be connected to the web-page.

## **MARLEEN JANSSEN**

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# Alumni seminar “Tactile language acquisition” in Groningen

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On September 25, 2019, the international Master’s program in deafblindness at the University of Groningen in the Netherlands held its annual alumni seminar. The topic of the seminar was “Tactile language acquisition”. The first speaker was Prof. Arnfinn Muruvik Vonen, who is a linguist and professor at the Department of International Studies and Interpreting at the Oslo Metropolitan University. His presentation, titled “Language must be sensorily accessible”, focused on how language can be made accessible for children with congenital deafblindness. Prof. Vonen emphasized that tactile signing has a different status for deafblind children than visual signing for deaf children. While visual sign languages are cultural languages, tactile sign languages are adaptations of visual cultural languages. Nevertheless, tactile signing seems to be the most accessible language for deafblind children. According to Prof.

Vonen, children with deafblindness need access to competent and aware tactile signers in order to develop tactile sign language. The second presentation was given by Gøran Forsgren, who works as a senior advisor for Statped, the Norwegian national service for special needs education, and is an alumnus of the Master’s program in deafblindness. His talk concerned the use of tactile language by people with congenital deafblindness. Mr. Forsgren explained that their linguistic expressions are often based on their embodied tactile impressions of the world, a phenomenon he refers to as “tactile iconicity”. To understand expressions of people with congenital deafblindness one can look at how they explore objects and how they construct signs. After the coffee break, participants attended a workshop in which they practiced recognizing tactile iconicity in a video clip of a young child with congenital deafblindness.



# Graduation day, Master's in Communication and Deafblindness

On September 26, 2019, five students of the Master's in Communication and Deafblindness program graduated at the University in Groningen, Department of Inclusive and Special Needs Education. Here is an overview of these master's students and their topics.

If you are interested in a thesis, you can contact either the authors or me. We are encouraging the authors to publish their thesis in the form of an article in the Journal of Deafblind Studies on Communication. Kim Tosolini has published her thesis in the latest issue.

**MARLEEN JANSSEN**

CHAIR OF THE DBI COMMUNICATION NETWORK

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- Kim Tosolini (the Netherlands): "Improving competences of newly qualified professionals"
- Hellen Shakele (Zambia): "How an intervention on the Tactile Bodily Modality can improve communication. A case study of a girl with congenital deafblindness in Zambia"
- Douglas Gawani (Zambia): "From communicative disability to communicative ability. An exploration into the implementation of knowledge about the communicative resources of a child with CDB by the use of focus groups"
- Cosmas Goliati (Malawi): "The impact of differences in cultural context on the interpretation of gestures"
- Rachel Kavanagh (Canada): "Exploring the voice of a child with congenital deafblindness in a multimodal interaction. A case study".

It was announced that the Master's program in the academic year 2019–2020 would have different content and criteria compared to the preceding years. The program would be more attuned to the regular Master's programs

in special needs education in Groningen and will have a new name: "Master's in Pedagogical Sciences (Deafblindness)". Its new curriculum coordinator will be Saskia Damen.

# Opening of the University of Groningen Institute for Deafblindness

**MARLEEN JANSSEN**

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On September 27, 2019, a new research institute opened its doors at the University of Groningen. It is an interdisciplinary institute for research and education in the area of congenital and acquired deafblindness. In the morning, several speakers explained why this institute is important. Kees Aarts of the University of Groningen, Ramses Vulperhorst of Royal Dutch Kentalis, and Angelique Koelewijn en Desirée Nobels of Deafblind Connect emphasized the development of expertise for people with deafblindness in its congenital, acquired and age-related forms. Marleen Janssen stressed the importance of collaboration at a national and international level in these times where in many countries the uniqueness of deafblindness as a disability is not recognized and remains unknown, while at the same time support in education and care is going through significant changes. She explained that the time is ripe for such an institute to consolidate what has already been achieved: 80 Master's graduates all over Europe and other continents, an alumni network, a Dutch Ph.D. program, the Journal of Deafblind Studies on Communication, and connections between smaller networks in the DBI Communication Network. It is time to lift up the existing knowledge to another level, spread it more, document it and investigate it further.

Marleen Janssen explained that the new institute is focusing on research and education activities:

- longitudinal research in the domain of communication, language, cognition and lifelong learning and other topics relating to special needs support and rehabilitation both in natural situations and in a research lab;
- collaboration with international research consortia where researchers and practitioners can work in different research networks to prepare special issues of journals and a new handbook about deafblindness covering themes such as: recent research in education and rehabilitation, tactile (sign) language, cognitive development, communication and language, identity and identification;
- identification of deafblindness: performing research but also spreading scientific information;
- providing manuscripts for journals and books with regular organization of national and international seminars or symposia.

Education activities:

- organizing and further developing the international Master's in deafblindness;

- organizing alumni seminars with interesting speakers and activities;
- developing an international Ph.D. Program on Deafblindness;
- organizing professionalization courses on topics such as interventions, assessment procedures and instruments in collaboration with other universities and care facilities.

Other speakers were Anne Nafstad, Jacques Souriau, and Marlene Daelman (representatives of the Groningen Study Group on Diversity in Communication) who gave a presentation on theory-based analyses of communication illustrated with interesting video fragments on the communication of a Belgian youngster with congenital deafblindness.

After that, Timothy Hartshorne (Professor of Psychology at Central Michigan University) and Christa de Geus (Coordinator of the CHARGE expertise center at the University Medical Center Groningen) gave an interdisciplinary presentation on “CHARGE, the Behavior Triangle”. More interdisciplinary presentations were given by Ronald Pennings (ENT consultant and surgeon at the Radboud University Medical Center) and Nicole Lo-A-Njoe-Kort (medical doctor and patient expert) about Usher syndrome

and building bridges between patients, doctors and rehabilitation. The morning was closed by two very interesting video-analytic demonstrations by Saskia Damen and Lisette de Jonge-Hoekstra (Ph.D. student at the Developmental Psychology Department of the University of Groningen; Psychologist at Kentalis).

As a surprise, Marleen Janssen was presented with a high royal award, the Order of the Netherlands Lion, which was a special moment not only for the one decorated.

After lunch the new research lab was opened, which is integrated with the University Ambulatorium of Groningen. Several young researchers gave parallel demonstrations and workshops on their approach to video analysis of interaction and communication: Kirsten Wolthuis (Ph.D. student), Kim Tosolini (Master's student), and Lisette de Jonge-Hoekstra.

In the next issue of Dbl Review, other smaller networks will report about their activities, such as the Groningen study group on diversity in communication.

If you want to learn more or have questions about this network, please contact Marleen Janssen, representing the Dbl Communication Network team: [h.j.m.janssen@rug.nl](mailto:h.j.m.janssen@rug.nl).



# VIRTUAL FORUM of the Dbl Ibero Latin American Network

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The Brasil Group for the Support to the Deafblind and Multi-Sensory Disabled and the Ahimsa Educational Association for Multiple Disabilities started hosting a virtual forum in tribute to Mike Collins with the support of Perkins International and the Lavelle Foundation in 2009. Held every three years, the fourth edition should have taken place in 2018; unfortunately, the university we sought to host the forum did not go through with our plan, so we postponed the forum to 2019. From November 10 to 16, we hosted our 4th VIRTUAL FORUM in tribute to MICHAEL COLLINS along with the 1st VIRTUAL FORUM of the Dbl Ibero Latin American Network. The virtual forum is a free-of-charge online event, people just have to register to receive a username and password to be able to access the platform. The forum consists of making texts and other materials available so people can download them, and there is a discussion session on the topic where participants are invited to comment, share experiences or ask questions. The latest event included full collaboration of the network members who so kindly shared their materials, articles, graphs, guides, books and booklets in order to reach out to more people in more countries. Some were in Portuguese and some were in Spanish. We are working so in the next editions we

can have all texts and materials in both languages. For the 2019 edition, the forum lasted seven days, from Sunday to Saturday. Each day there was a main theme to be discussed and supporting texts/materials were provided accordingly. After the theme was open, it stayed open until the end plus one extra week for those who did not have the opportunity to download all the materials. The themes were also proposed by the members, namely: Rights, Causes, Inclusion, Detection/Census, Accessibility, Academic Research, and Fund Raising. One hundred and forty-four people applied for registration, although only 50 actually took part in the forum. Most participants were from Brazil, although there were a few from Argentina, Mexico, Guatemala, Peru, Colombia and Venezuela. We hope we can reach those who seek information so that more and more people with deafblindness and people with sensory disabilities can receive quality services to improve their quality of life.

Thank you and please give us a like on our Facebook page. There are many other countries including some in Africa and Asia that could benefit from our forums, campaigns and resources, both in the Portuguese and Spanish languages.

Till next time, with more news.

# In order to build an identity, one must be seen, heard and mirrored

The Nordic CHARGE network convened in Oslo on November 7, with many participants accessing the event online. In addition to those physically present, many people watched and listened through a link where they could submit questions and comments.

REGIONAL  
CENTER FOR  
THE DEAFBLIND,  
UNIVERSITY  
HOSPITAL OF  
NORTH NORWAY

The Nordic CHARGE network collects and shares knowledge about CHARGE syndrome in the Nordic countries. The group's main areas of interest are special behaviors, parents' situations and needs, pain and pain research, the significance of the tactile mind in

communication and the social aspects of living with CHARGE.

The conference was opened by Maria Creutz, senior advisor at the Nordic Welfare Centre, and Marianne Disch, assistant director from Statped, the national service for special needs education in Norway.



Sonja Friberg, Jette Nørgaard, Anette Sølgaard, Kirsten Costain, Monika Estenberger, Lynn Skei and Mona Andreassen Hellebust

## Seeing communication on a deeper level

The first talk was given by Kirsten Costain, a senior advisor with Statped. One of her key statements was “In order to build an identity, one must be seen, heard and mirrored.” According to Costain, it is important to understand one’s own “emotional world” and to understand that others can have similar feelings. Further, she stressed the importance of developing a vocabulary for the “chaos in my mind”, which can be achieved by working with a teacher to learn social codes.

Costain presented findings from her extensive research and proposed that all “research is interpretation.” In response to critics who claim that researchers tend to be too subjective, she claimed that interpretation is in itself a scientific method. Costain went on to propose that it is important to see the child’s communication on a deeper level than that which sign language can provide. “Semi-structured interviews are one way to achieve this,” she said, adding as a word of caution, “Children often give us the answers they think we want.”



Psychologist Lynn Skei thinks there is more than meets the eye.

## Making What’s Implicit Explicit

Another contributor, Lynn Skei, a psychologist with the Signo Foundation, took the stage along with Jette Noergaard from CDH and Annette Sølgaard from CDG in Denmark to present Connie’s story. Connie is a Danish woman in her thirties who lives in an institution with other women who have various disabilities.

Skei described Connie as goal-oriented and strategically minded, and explained that “there is more than meets the eye” while showing pictures of Connie, as well as Connie’s own photographic art. Skei showed

a series of videos of Connie interacting with a fellow resident, with the aim of illustrating her tenacity and goal-oriented behavior.

“Ever since we were babies, we have experienced that when we make certain sounds, or look at our mother in a certain way, something happens. We’ve learned lots of rules. If we haven’t learned those rules, then we must be taught. The unspoken rules must be described to us,” said Skei. “The work is about making what’s implicit explicit.”

Skei went on to explain that, after being exposed to the same events numerous times, a



script can be formed. And that it takes time to learn the script. “Don’t tamper with the script. We are not good enough at understanding how important these ‘small’ changes can be,” she said.

Skei also proposed that people with CHARGE often have “pleasing” behavior. She said that choosing to be a follower is a good strategy,

because when you struggle with mentalization, it’s hard to understand what is expected of you.

In conclusion, Skei made an important statement as encouragement to professionals who work with people with CHARGE syndrome: “The spikes are not artefacts but indicate cognitive capacity and potential!”



Monika Estenberger and Sonja Friberg described the children they had met as “thorough and reflective, positive and honest”.

### Children Eager to Tell their Stories

Other contributors on stage were Monika Estenberger from Sweden’s National Centre on Deafblindness and Sonja Friberg from the National Agency for Special Needs Education and Schools in Sweden. They presented some of the findings from their qualitative research.

They had met children who were interested and eager to tell their stories: “They were thorough and reflective, positive and

honest,” according to Estenberger and Friberg, who presented specific quotes from the interviews in which children talked about the syndrome, self-esteem, emotions, social relations and getting confirmation from others.

Throughout the day, several participants brought up the importance of equal relationships and how hard it can be for children with CHARGE to find them.

### Facts:

- The conference was a cooperation between the Nordic Welfare Centre and Statped, the national service for special needs education in Norway.
- Statped made it possible to stream the conference.

# One-year Master's program in deafblindness

## SASKIA DAMEN

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In September 2020, the University of Groningen in the Netherlands again offers a one-year international master's program in deafblindness. The program is taught in English and is open for people from all over the world who are interested in acquiring in-depth knowledge about people with deafblindness and professional skills in assessment, intervention and scientific research for this target group. The program consists of a combination of classroom and distance education, enabling the participation of students from all continents and those who want or need to combine study

and work. The program starts with one month of full-time interactive lectures and practical assignments at the University of Groningen. After this month, students work on practical assignments and a research project in their own countries. Lecturers of the master's program are international experts in the field of deafblindness and sign language. For more information on this master and admission requirements (the deadline for admission is May 1, 2020), please visit <https://www.rug.nl/masters/deafblindness/> or contact the curriculum coordinator Saskia Damen at [s.damen@rug.nl](mailto:s.damen@rug.nl).

# Call from the Rubella Network

## TREES VAN NUNEN

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After some silence from the Rubella network, we are very pleased that Edwin Osundwa (director of Sense International Kenya) has made himself available as the new network leader. First of all, we are looking for a person who wants to support Edwin to breathe new life into the Rubella network. In addition, we would like to ask everyone who was a member of this

network to sign up again if you are still interested in its activities. Due to changes in network leaders in the past, we are no longer aware of who the network members are. New interested people are of course also welcome to join. If you want to become a member of the Rubella network, please write an email to Edwin ([edwin@senseint-ea.org](mailto:edwin@senseint-ea.org)).

# Evidence-based practices for assessment of children and youth who are deafblind

Article No. 2 in the assessment series for Deafblind International

## Introduction

This article, the second in a series of articles on assessment, will address evidence-based practices that are specific to assessment, determined by an evaluation of research on deafblindness (based on publications that appeared in English, 1990–2013). This review was conducted for the CEEDAR Center (with CEEDAR standing for Collaboration for Effective Educator Development, Accountability, and Reform; [www.ceedar.education.ufl.edu](http://www.ceedar.education.ufl.edu)), a U.S. federally funded Center charged with disseminating the state of evidence on instructional practices. The results of this analysis of research appear in the Innovation Configuration on Sensory Impairments (Ferrell, Bruce & Luckner, 2014). The level of evidence (emerging, limited, moderate or strong) for assessment

practices was evaluated, applying a rubric provided by the CEEDAR Center to evaluate the quality of the research. All evidence-based practices (EBPs) in assessment (specific to deafblindness) are at the emerging level, meaning that they are derived primarily from professional literature with little evidence grounded in research studies. One reason for this low level of evidence is that deafblindness is a very low-incidence disability of great heterogeneity, making it difficult to conduct larger-scale research studies (especially with meaningful comparison groups) that would result in higher levels of evidence. Another reason is that assessment practices in deafblindness are inherently difficult to study because assessment must be highly individualized and contextualized for this population.

## Pros and cons of formal and informal assessment instruments (M)

While both formal and informal assessment instruments and procedures may be beneficial when assessing a learner who is deafblind, the first EBP is that the *sole use of formal assessment instruments is inappropriate for this population*

(Ferrell et al., 2014). Some formal assessment instruments include data on norming groups, but these seldom include children who are deafblind. Formal assessment instruments include highly structured procedures used for



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administration, scoring and interpretation purposes (Bruce & Stutzman, 2018). Data may be collected through observation, direct testing, interviews, surveys and informal reports, according to the administration guidelines of each assessment instrument. Some instruments do not measure partial performance, either partial performance of the item or prompted performance, creating frustration when measuring what the child can do. In our field, we sometimes modify test items because the child displays the knowledge or skill in a way that is different from how the item is worded. Whenever we change administration procedures, we create issues of validity and reliability. Additionally, scores with great deviation from the mean also suggest negative validity. In addition to cultural and experiential biases, formal assessment instruments may not evaluate what the student is learning or how the student learns. Of course, we can use formal instruments to identify what the child can currently do, without providing numerical scores that may not be accurate (due to changes in administration of the assessment instrument) or may even be harmful to the child or parent(s). Whenever a child is being directly tested, someone who knows the child well should be present to support effective assessment processes and to provide emotional security (Bruce, Luckner & Ferrell, 2018).

### Environment

Ferrell et al. (2014) identified two assessment EBPs specific to environmental considerations. The first is that *assessments of the individual who is deafblind should occur in natural environments* (where specific activities would naturally occur and are familiar to the child) and that *assessment should occur across multiple environments* (due to variation in performance across environments). The second EBP is that the *environments themselves must be assessed for*

The second EBP is that *informal assessment instruments and procedures are essential to gaining a complete understanding of the child's knowledge and skills*. Informal assessments are less structured than formal assessments but are more context-considerate. Dynamic assessment approaches, such as the van Dijk child-guided approach to assessment, allow the evaluator to make changes in administration based on the student's response. The van Dijk approach investigates biobehavioral state, orienting response, learning channels, approach-withdrawal, memory, interactions, communication, and problem solving (Nelson, van Dijk, McDonnell & Thompson, 2002). Person-centered assessment approaches (including personal futures planning) support the recognition of valued life outcomes, contexts of participation, friendship and support circles and include input from the individual who is deafblind, family members and friends. Functional behavior analysis (FBA) is a form of informal assessment that determines the functions of behaviors for the child (such as seeking tangibles, seeking attention, needing less or more sensory stimulation and escaping from the task). Researchers or assessors may use information from the FBA to create a positive behavior support (PBS) plan for the student who is deafblind.

*their visual, auditory and tactile characteristics and for the potential impact of those characteristics on the student*. Thorough assessment of each environment also supports planning for communication intervention (such as the content/messages that are most functional in each environment) and for planning appropriate adaptations and accommodations. Please see the section of this article on accommodations.

### Identifying additional disabilities

One EBP on the identification of additional disabilities appeared in the analysis by Ferrell et al. (2014). It advises *caution when*

*diagnosing additional disabilities in learners who are deafblind*. This is because the impact of deafblindness may result in displayed

characteristics or behaviors that make the diagnostic criteria of the additional disability inappropriate. For example, a child who is deafblind could have the additional disability of autism but could also demonstrate some of the characteristics of autism (such as poor eye contact or lack of responsiveness to others) completely because of the

sensory losses. Thus, it is critical to consider both the inclusion and exclusion criteria for identifying an additional disability in the context of what we know about the impact of deafblindness. Teams considering the identification of an additional disability in a child who is deafblind should include a professional with expertise in deafblindness.

## Family

While family input is important to all assessment procedures, Ferrell et al. (2014) identified an EBP specific to early childhood assessment. It is that the team *consider the family's strengths and needs and that together they identify meaningful outcomes and appropriate educational supports*. This will include the identification of appropriate

communication strategies, environmental accommodations, instructional targets for enhancing visual, auditory and tactile development and the exploration of assistive technologies (Anthony, 2016). In the U.S., the Individualized Family Service Plan (IFSP) will articulate resources needed by the family.

## Specialized assessments in deafblindness

*Children who are deafblind require functional vision assessment (FVA) and functional hearing assessment to supplement audiology and ophthalmology reports* (Ferrell et al., 2014). As part of FVA, children with cortical visual impairment (CVI) will require assessment of the characteristics associated with CVI, such as latency, attention to movement and differential responses to color (Roman, 2017) to guide program development.

*Learning media assessments (LMAs) should be conducted on each child who is deafblind, and that assessment should include an analysis of the child's preferred learning channels (visual, auditory, and tactual) to support the team in identifying primary, secondary and tertiary modalities for learning*. Each of these specialized assessments are EBPs identified in the analysis by Ferrell et al. (2014).

## Accommodations and assessment

Very little research on accommodations for assessment of children who are deafblind has been published. Emerging EBPs include the need to ensure a match between the accommodations listed on each child's

Individualized Education Plan (IEP) and those used in assessment (including the need to offer consistently appropriate enlargement) and to format text in ways that are familiar to the child (Bruce, Luckner & Ferrell, 2018).

## Conclusion

The field of deafblindness has an emerging level of evidence-based practices in assessment, including identified promising practices in balancing formal and informal assessment instruments and procedures, assessment of the characteristics of learning environments, involvement of the family in early childhood assessment, use of FVAs and LMAs for every child who is deafblind, the importance of

exercising caution when identifying additional disabilities in children who are deafblind and ensuring that accommodations used in assessment match those on the IEP. More research is needed on each of these practices, especially on the family's input on assessment, accommodations and on the effectiveness of specific informal assessment approaches such as person-centered planning.



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# Sibling relationships in families raising children with dual sensory impairment

The article is devoted to sibling relationships in families raising children with multiple complex developmental disorder (MCDD), including combined sight and hearing loss.

In psychological science, there are very few studies of sibling relationships focusing on brothers and sisters of children who are deafblind (Banta, 1979; Klein, 1977). Most foreign studies of sibling relationships in families raising children with developmental disabilities focus on the relationships between typically developing children and their siblings with intellectual disabilities (ID).

In the Russian psychological and pedagogical literature, there are no works (either theoretical or practical) on the problem of sibling relationships in families with deafblind children, as well as a system of assistance to families in raising healthy siblings of a child with sight and hearing loss.

This article presents some empirical data on the features of communication between children with hearing and vision disorders and their typically developing siblings.

Before starting the research, we assumed that the characteristics

of relationships and communication may depend on the age of a typically developing sibling. Older siblings may be more involved in caring for a sibling who is deafblind, but they will be more likely to dominate in interaction and display more initiative in communication. The common means of communication available to both in a sibling pair should also be an important factor of interaction.

To study the features of communication between children with sight and hearing loss and their siblings, we have selected and adapted the following tools: the Brother-Sister Questionnaire by S.A. Graham-Bermann and S.E. Culter for children older than 6 years, the Kinetic Family Drawing (KFD) by R. Burns and S. Kaufman, a questionnaire survey of mothers, and analysis of video recordings.

The study involved six families with one child who is deafblind and another one who is typically developing and ten families with



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siblings who are both typically developing. Children were between two and 14 years old.

According to the results of the Sibling questionnaire (6+), there are no significant differences in attitudes towards typically developing siblings and children who are deafblind. With regard to attitudes towards siblings without sight and hearing loss, the questionnaire shows a slightly higher level of empathy.

Siblings without sensory challenges show a positive attitude towards siblings who are deafblind, and we assume that this is the result of the fact that parents practically do not assign the responsibilities of care for a deafblind child to those without sensory challenges (according to the questionnaire for mothers).

The Kinetic Family Drawing showed the following results. In both groups, children rarely drew pictures of themselves and their siblings engaged in a common activity, except for one girl who had a deafblind brother and depicted them trying to take a toy from each other.

All videos provided by parents showed situations of positive interaction between deafblind children and their siblings without sensory challenges.

We noticed that the role and degree of initiative of each sibling in communication situations depends on the availability of common means of communication. Most children who have deafblind siblings take a dominant position, organize interaction and do not always notice the communicative manifestations of a sibling who is deafblind. The exception was

a couple of boys playing different tactile and active games, where the older brother always waited for the responses of the younger deafblind sibling to continue the game or repeat the action.

It was usually noticed that siblings without sensory challenges tend to interact with each other in equal measure of communicative initiative and involvement.

The research results in the following conclusions:

1. Regardless of the presence or absence of sight and hearing loss in one of the siblings, the relationship between two children from the same family is usually positive and characterized by the presence of attachment.
2. The degree of initiative in the interaction of both siblings does not depend on the age of the child without sensory challenges. Even younger siblings take a dominant position in communication with a child who is deafblind.
3. We assume that the degree of active participation in communication depends on the presence of common means of communication (in our study, on the level of development of speech and communication skills of a child who is deafblind). A child with dual sensory impairment who has a little command of oral speech is much more likely to influence the process of interaction than a child who does not use spoken language. Unfortunately, there were no siblings without sensory challenges who had special means of communication among our participants.

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# Transition from school to quality adult life for youth with deafblindness

Creating and Promoting Evidence-Based Practices of Planning and Programming.

All youth, regardless of culture, country, or any other contributing factor will eventually evolve from adolescence to adulthood. The developmental phase in which an adolescent will grow from a teenager to full adulthood is referred to as the in-between age. This would appear to be a critical developmental stage since it leads to such adult outcomes as employment, marriage, parenthood, and overall independence. When there is difficulty in transitioning through this in-between phase of development, young adults often can experience a diminished quality of life. Although it is recognized that different cultures, communities and regions of the world have varied expectations of their emerging adults, every adolescent will transition to an adult life. Youth with deafblindness, who enter into the emerging adult phase of development, most often are faced with unique challenges that relate to the lack of access to people, places and information. A deafblind emerging adult often has a history of diminished access to education, needed services and supports that would prepare them for realizing adult roles. Reduced opportunities, low expectations, and other factors can strongly

influence the youth with deafblindness' transition to an adult quality of life. In particular, many young adults with deafblindness have not had the opportunities to establish meaningful relationships or a social network which is key to achieving a successful adult life.

Attention to this critical area of promoting the successful adult quality of life outcomes has been increasingly recognized by families and professionals. Despite the attempts of a few researchers in this area, little is known about the collective adult or post-school outcomes of youth with deafblindness. The promising practices in promoting effective efforts to assist the emerging adults' transition to quality of life are documented in the literature, however, there needs to be more research to better understand the unique approaches that are necessary for individuals who are deafblind. The following practices are considered critical to assisting youth with deafblindness in their transition to adult quality of life:

- **Person-Centered Planning:**  
There is strong indication and agreement among professionals, that robust person-centered planning is a key factor in



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achieving successful transition, and furthermore, planning must be a continuous process rather than just a point-in-time. Person-center planning is an approach to planning that is based in a problem-solving process based from the individual rather than from available services or programs. There are many avenues to achieve person-centered planning; however, they must reflect the individuals' choices, likes, and desires.

- **Social Network Development:** Opportunities for developing meaningful friendships and relationships with others through planned and deliberate efforts are required for individuals who are deafblind. Although these opportunities are often easily accessed by hearing / sighted youth, those that are deafblind necessitate support of others. A circle of supportive people in a young adult's life seems to be directly related to achieving a quality of life.
- **Development of Skill of Self-Determination and Self-Advocacy:** Youth with deafblindness must be provided opportunities to make personal decisions have real and informed choices, and exercise an appropriate level of control in

their lives. This is a contributing factor to achieving success in adulthood.

- **Opportunities for Independence within the Community:** All youth benefit from gradual independence within their communities through planned and supported employment experiences, independent or supported travel, and access to community services. Without these experiences, the youth with deafblindness is often over-controlled and under influenced.

In the absence of opportunities to access people and places, deliberate and explicit instruction in the domains of adult independence, deafblind emerging adults will find it difficult to achieve a adult quality of life. Therefore, deafblind youth along with their families and professionals must undertake the challenge to assure that emerging youth with deafblindness can expect the choices and characteristics of adult life as everyone else is offered. These include meaningful relationships, access to post-secondary education, employment, and full participation in community life.

**Note:** This article is a summation of a lecture presented at the 2nd Annual Young Researchers Conference for Deafblindness. For more information on this topic, email the author at [JerryGP53@gmail.com](mailto:JerryGP53@gmail.com).



# School at the edge of the forest: an exploration into the outdoor activities used at Skådalen School for Deafblind Children in Oslo, Norway

## Introduction

Skådalen school in Oslo, Norway, is a school for pupils who are classified as congenitally deafblind. This article presents an overview of the outdoor activities that are currently undertaken at the school. It is the first stage of a larger project that aims to examine and develop outdoor activities with pupils who are congenitally deafblind. Previous research on using outdoor activities with people who are congenitally deafblind has focused on the experiences of adults (Gibson, 2000; Gibson, 2005; Gibson & Ask Larsen, 2009; Gibson & Nicholas, 2017; Gibson, 2018). These studies have shown a range of benefits that can be achieved through the use of outdoor activities:

- Communication development (Gibson, 2005)
- Learning opportunities (Gibson, 2000; Gibson, 2005)

- Stimulating experiences (Gibson, 2000; Gibson, 2005)
- Relationships (Gibson, 2000)
- Health (Gibson, 2000)
- Personal and social development (Gibson, 2000; Gibson, 2005)
- Comfort zone (Gibson & Ask Larsen, 2009)
- Autobiographical memory (Gibson & Nicholas, 2017)
- Tactile language development (Gibson, 2018).

We are interested if these benefits found with adults would be different from what we found with school pupils at Skådalen. There are currently 10 pupils at Skådalen school, each with a small team of teachers coordinated by a contact teacher. It would be wrong to say there is an outdoor

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program at Skådalen School. The wide range of abilities and different needs of each of the pupils means a single program would not be appropriate. It would be more accurate to say there are ten different outdoor programs or approaches, one for each pupil, in the same way that each pupil has their own IOP (Individuell Opplæringsplan - Individual Learning Plan). The subject areas in these plans are set by the Norwegian Department of Education:

- Norwegian.
- Mathematics.
- Music.
- Physical Education.
- Natural Science.
- Social Studies.

### Methods

There were two strands to the data collection: one relating to the pupil's individual activities and one to group activities. The data collection, analysis

### Group activities

The list of group activities run by the Activity Group was collated through the course of the school year 2017–2018 as they took place. The first activity recorded was the “apple day” on October 20, 2017, and the last

### Individual activities

Information on the individual pupil activities were collected by a simple questionnaire. The questionnaire was distributed amongst each pupil's staff team via the contact teacher. The contact teacher for a pupil who had left the school the previous year asked if they could also complete a questionnaire giving us information for 11 pupils. The questionnaire focused on three main questions:

- Food & Health.
- Art & Craft.
- Christianity, Religion Spirituality & Ethics.

These subjects and individual outdoor activities are planned and implemented by the teachers in the pupils' team. There are also group “outdoor activities” for all the pupils together that the Activity Group organizes. The Activity Group is made up of four teachers (including both authors) who organize and facilitate group activities. This article examines both the outdoor activities currently undertaken at the school by individual pupils and the program of group activities. The study has focused on what different activities the pupils do, why they do them and which subject areas are addressed through the activities.

and results sections will each examine these two strands separately while the discussion and conclusions will be more general.

a “group picnic” on June 20, 2018, with 23 different activity days in total. Once the list of group activities was complete, we began to look for categories according to the aims of the activity.

1. Do you use outdoor activities with your pupil?
2. What outdoor activities do you do?
3. Why do you do these activities?

Each pupil was given a number to maintain their anonymity. All the questionnaires were collated, and the answers grouped. We then listed all the answers for each question. Emerging categories could then be identified and noted.

## Focus groups

The emerging categories from both the group and individual activities were discussed with two different focus groups. The first focus group was made up of three teachers who between them worked with each of the pupils. We presented them with the results from the questionnaires and

our initial categories. Next, we presented the data, our initial categories and the comments of the first focus group to the second “expert” focus group which consisted of the PE teacher and a teacher who had also organized outdoor activities for deafblind people over many years.

## Group activities

There were 23 activity days in total with some of the activities being repeated, giving 13 separate activities. We grouped the activities into five initial categories, which were:

- physical
- cultural
- communal
- learning
- task completion.

The category “physical” included physical challenges, trying a new physical activity

and learning physical skills. The “cultural” category was for activities that are typically Norwegian or related to the time of the year and the season. The category “communal” addressed activities that involve contact with other students and teachers. The “learning” category was given to activities that involved learning something about a theme and talking about this theme both before and after the activity. If the activity was a route the student had to follow or an exercise they had to complete, “task completion” was the category. Table 1 shows which initial categories were ascribed to the 13 different group activities.

**Table 1.** Initial categories of group activities

Group activity	Purpose categories
Apple day	cultural, learning, task completion
Frisby golf	physical, task completion
Climbing day	physical
Treasure hunt	learning, physical, task completion
Campfire	cultural, communal
Christmas tree hunt	cultural, physical
Building a snow cave	cultural, communal
Curling	physical, cultural
Olympic sports day	cultural, physical, task completion
Easter egg hunt	cultural, learning, physical, task completion
Taste and smell route	learning, physical, task completion

Group activity	Purpose categories
Bicycle day	physical, communal
Picnic	cultural, communal

## Individual activities

Each of the three questions from the questionnaire is now examined individually.

- **Question 1.** Do you use outdoor activities with your pupil?

All 11 teams answered yes, their pupil used outdoor activities. There were however two replies with caveats. One pupil's (pupil 6) use of the outdoors was weather-dependent as they are very sensitive to cold. Another pupil (pupil 10) had not used outdoor activities

regularly in the last year due to anxiety issues but had done so extensively prior to this.

- **Question 2.** What outdoor activities do you do?

There were 18 different activities initially recorded in the questionnaire. These were grouped into five categories: Sports, Trip, Environmental Activities, Friluftsliv (Outdoor Life) and Communication (see Table 2).

**Table 2.** Initial categories of individual activities

Sports	Trip	Environmental Activities	Friluftsliv (Outdoor Life)	Communication
Climbing	A trip (walking or wheelchair) in the forest	Experiencing and interacting with nature, weather and seasons	Picnicking	Communication and language before, during and after the trip
Skiing	A trip (walking or wheelchair) in the school area, including the adventure path around the school	Collecting objects	Using a map-stick / learning a route, map-making	
Running	A trip (walking or wheelchair) in the city	Working and experiencing the growth in a school garden	Making a fire	
Horse riding	A trip with the tube	Playing outside on the swing		
Biking				
Sledging				

- **Question 3.** Why do you do these activities?

The answers to question three gave us 14 different goals or aims. We refined these

down to seven categories or broader goals to describe why our students use outdoor activities (see Table 3).

**Table 3.** Categories of goals and aims of individual activities

Categories	Goals and aims from the questionnaire
Pleasure and fun	<ul style="list-style-type: none"><li>• Pleasure of being outside</li><li>• Challenging borders and experiencing success</li><li>• Playing and having fun</li></ul>
Environmental goals	<ul style="list-style-type: none"><li>• Learning about the world around us (nature, weather and seasons) and making contact with it</li><li>• Making contact with an animal</li><li>• Following the process of a growing plant or tree (start – middle – end)</li><li>• Challenging borders and experiencing success</li></ul>
Sensory goals	<ul style="list-style-type: none"><li>• Sensory experiences: movement and speed, tactile, smell, sounds and visual</li><li>• Visual training</li><li>• Learning differences (big/small stone) and shapes in nature</li></ul>
Physical goals	<ul style="list-style-type: none"><li>• Physical training</li></ul>
Communication	<ul style="list-style-type: none"><li>• Communication and a shared experience</li></ul>
Mobility and orientation	<ul style="list-style-type: none"><li>• Mobility and cognition, finding your way, a mental map of the surroundings, predictability/feeling of control</li><li>• Visual training</li><li>• Map-stick use</li></ul>
Formal subjects and curriculum	<ul style="list-style-type: none"><li>• Subject based (Norwegian, maths, arts and crafts etc.)</li></ul>

Focus group feedback

The two focus groups helped us refine our thinking in several ways. The first focus group suggested we could define the categories of activity goals more clearly. They also coded almost all the activities as Physical (both individual and group activities), Learning (group activities) and Formal Subject/Curriculum (individual activities).

This led to a discussion, where the following ideas were proposed:

- We are a school – everything is (or should be) learning.
- We are talking about activities – therefore everything is, to an extent, physical.



The members of the first focus group did not always agree with each other on which categories different activities could be in – not only do we have 10 very different pupils with their different needs but we have 25 teachers with their own teaching styles and focus, who often use and view the same activities in different ways.

The two members of the “expert” focus group both agreed that all the activities have a physical element and all the activities have a learning element. They also noted:

- The category an activity fits into can depend on where you put the focus (for the pupil or the activity).
- We (the Activity Group) might sometimes need to facilitate the cognitive aspects to bring them to the fore.
- All the categories can fit in the individual learning plans (IOP) and teaching plans.
- Cultural learning and communication are very important aspects with our pupils.

### Discussion

This explorative study on outdoor activities with deafblind children at Skådalen school in Oslo taught us a lot about the activities that occur at the school and the different themes that can be addressed through teaching outside. The group activities and individual activities were given categories (Tables 1 & 2). Then goals for the individual activities were also grouped into categories (Table 3). These three groups of categories were then combined together with the curricular areas that the activities seek to address into five final areas of focus. These themes are:

- Physical
- Cognitive
- Communication
- Environmental
- Social

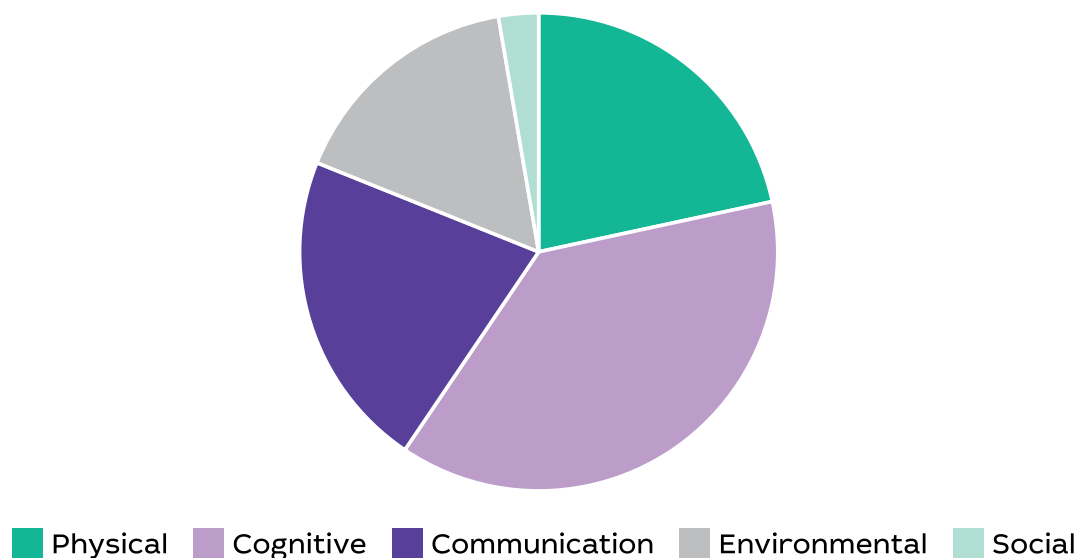
The theme *physical* includes sports, trips, physical goals, mobility and orientation. The theme *cognitive* includes learning, task completion, all the curricular subjects and sensory goals. The theme *communication* is a central area with all our deafblind pupils. Communication is seen in a wide perspective,

it occurs in the subject area of social studies but also in every other part of our education, and its development is our main goal at the school. The theme *environmental* includes natural science, sensory experiences and other environmental activities. The last theme is social. This includes communal and cultural activities, trips with a group and the curricular area social studies. The term *friluftsliv* (from Table 2, Individual Activity Categories), meaning outdoor or nature living, is very important in Norway, and it is beyond the scope of this article to define it in more detail. *Friluftsliv* is hard to put in one of the themes, it has aspects of all five themes. Pleasure and Fun (from Table 3, Individual Activity Goals) was also something that could fit into all the themes – especially when working with pupils with such complex sensory impairments.

This study reinforced the idea that each teacher or team can have a different focus during the activities with their different pupils depending on the needs, interests and abilities of that pupil. The same is true for group activities. To illustrate this different focus in outdoor activities, we would like to present two examples of different activities with different pupils.

**Example 1.** The taste and smell route (a treasure hunt with herbs)

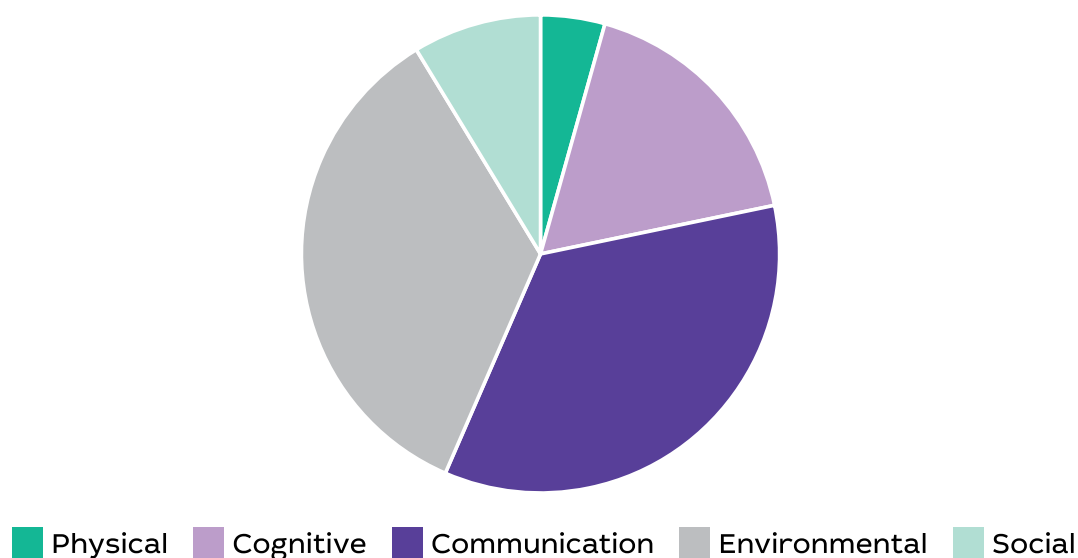
Pupil A:



Pupil A (aged 17) has some impaired mobility but has recently started to walk after a lot of training in the last year. This means that following a route walking through the forest is very much a physical activity. The pupil has also begun to communicate more using sign, fingerspelling and braille.

This pupil uses the two-handed alphabet to spell all the different plants and herbs that they meet on the way. The pupil and the teacher talk together about the plants, taste them and learn about shape, taste and the spelling of the names and relevant signs.

Pupil B:

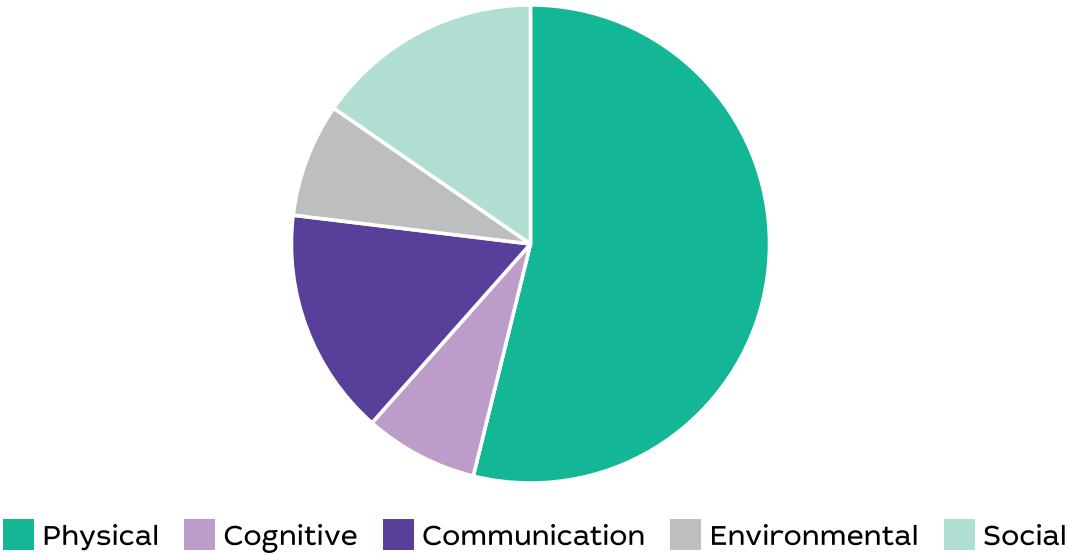


Pupil B (aged 17) uses a wheelchair, has severe physical impairments and is very tactile defensive. The trip in the forest is much less about the physical aspect although they enjoy the physical sensation of driving over

rough ground. The focus is on encouraging the pupil to interact with the nature around and talk about these experiences. Tasting and touching something unknown is a challenge for this pupil.

Example 2. The bicycle day activity

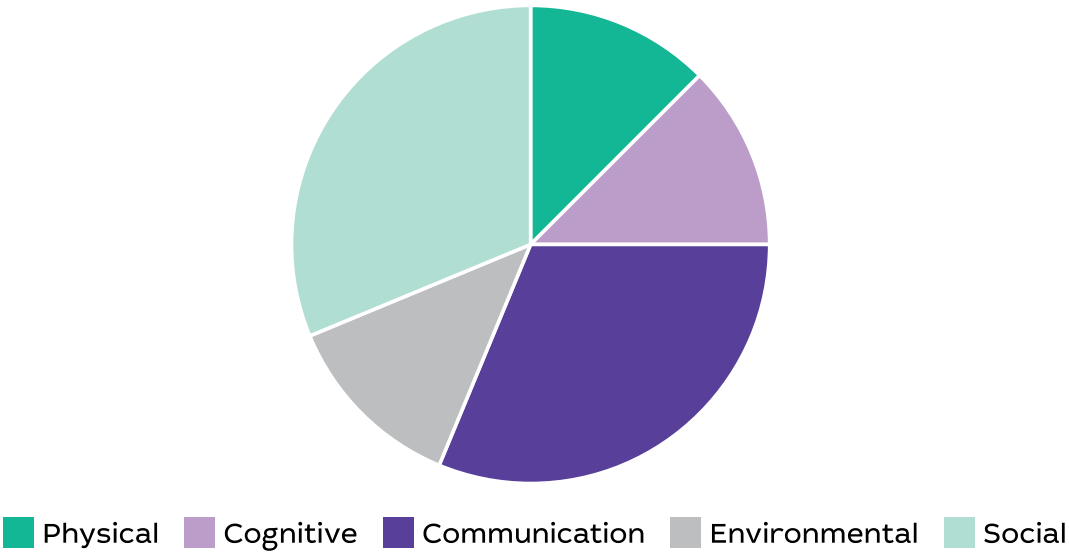
Pupil C:



Pupil C (aged 13) loves biking and physical activities. The bicycle day is a social event where all the students and teachers gather outside, enjoy some food and drinks and bike around a route with different exercises. The experience is used as a

subject to talk about with the pupil after the event. The pupil is mostly on the bike, riding around the different objects and exercises. The pupil enjoys meeting other pupils and teachers and enjoys the food outside.

Pupil D:



Pupil D (aged 19) uses the bicycle day as an arena to be social and communicate with different teachers and pupils. The physical aspect of this activity does not seem to be as important for this student as the social.

We can see from the examples above that when organizing the activities, we must be aware of the five different focus areas and how they might differ for each pupil.

## Conclusions

This article found that all the pupils at Skådalen School engage in outdoor activities both as part of their individual timetable and through group activities. While the types of activities are similar, the focus during the activities can vary. Although this is only an exploratory study, we have begun to see the emergence of themes. The themes we found were similar to those found in the research with congenitally deafblind adults. Of the nine areas of benefit identified in the research with adults, only health does not fit obviously into one of our themes. However, the theme Cognition includes curricular subjects, of which “food and health” is one. Also, aspects of Health from the adult research could also fit into the theme Physical from this project.

At this early stage we can see different ways in which the teachers are using outdoor activities with the deafblind pupils at Skådalen

school, and a range of benefits is emerging. This leads to a number of possible further areas to explore:

- Further checking the validity of the themes
- Comparisons with mainstream schools that use outdoor activities
- Comparisons with other schools for deafblind children
- Exploring more the links between activities and school subjects.

Do you work at a school teaching pupils who are congenitally deafblind? Do you currently use outdoor activities, or would you like to use outdoor activities in a more structured way? If you would you like to be involved in the next stages of our research project, please feel free to contact Joe Gibson ([joseph.william.gibson@statped.no](mailto:joseph.william.gibson@statped.no))

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# Javier García Pajares

Javier García Pajares is a 28-year-old deafblind man who started having hearing loss when he was 13 years old, and vision loss when he was 15. He studied a joint degree in Law and Business Management at the Universidad Autónoma de Madrid. He also finished a three-month Erasmus Program at Regent's University of London in 2017. Javier is currently working as a Legal Adviser in ILUnion and has also been the chairperson of FASOCIDE's Youth Committee since January 2019.



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Photo:  
Javier on the  
top of the  
mountain

**FASOCIDE: Of all the barriers that deafblind people have to face in their daily life, which ones do you think affect them most during their youth?**

Javier: I think that perhaps the biggest barrier is the negative attitude of people. When you find a barrier, it is nothing other than a barrier that you can break. Nevertheless, there is nothing you can do against a negative attitude. I am aware that I may have communication problems, for instance, because everybody does not know how to communicate with me. I usually meet people who tell me "we will learn someday..." and others who directly tell me, "teach me". I strongly believe that the latter can change the world.

**FASOCIDE: In recent years you have become a leader of Spanish deafblind young people thanks to your passion for mountaineering. Were you already into these**

**activities before your deafblindness or how did you encourage yourself to do them? How has this changed your life?**

Javier: I got into climbing thanks to my deafblindness. This may seem strange, but José Antonio, a psychologist who works in O.N.C.E., helped me to rethink my life through climbing, shortly after my deafblind condition appeared. While climbing together every Friday morning, I learnt that it is possible to reach as high as you want.

After that, ten years later, I met José Antonio again and I took the leap from climbing to mountaineering. Mountaineering teaches you a very important life lesson. It is a metaphor for life in which you set yourself a goal, you make a big effort in order to achieve it, but you do not forget to enjoy the path.



**FASOCIDE:** Of all the experiences you have had mountaineering, which ones stand out and why?

Javier: People were astonished when I climbed seven mountain peaks of over 4000 meters in the Alps in just over six days, or when I climbed to the top of Mount Elbrus, the highest mountain in Europe, even though the Russian mountain guide we hired had to turn back because he was exhausted. However, the truth is that you can run into trouble on any mountain, no matter the height. I felt a ray of lightning strike the ground a few meters from where I was standing, and I was afraid when ice cracked under my feet knowing that I could suffer a 50-meter fall. Although I believe that what makes my achievement more impressive is that my will to keep moving forward outweighs my fear.

**FASOCIDE:** What kind of support did you have in order to be able to take part in this activity and how did you achieve it?

Javier: Positive attitudes change the world, and José Antonio definitely has one. He lent me a hand and since then, he has been my mountain guide. José Antonio usually goes before me in order to guide me, while another person is behind me making sure I am safe, and then a third person, Cristina, my deafblind interpreter from FASOCIDE, helps me with the communication process.

Then we have the economic issue, because mountain activities are usually very expensive. We are a keen group, and our aim is to enjoy what we do and share it with others, but we also devote a lot of time to trying to get funding. Nevertheless, we pay the biggest costs ourselves because it is something we are passionate about.



Javier with his deafblind interpreter Cristina and the mountain guides





Javier communicating using tactile fingerspelling

**FASOCIDE: Do you do or would you like to do any other sport?**

Javier: The projects started with mountaineering activities, but little by little we are opening up to new sports. Last year I was able to go parachuting. For me, jumping meant letting go of my fears in order to follow my dreams. Furthermore, I also went sport climbing and traditional climbing, looking for my preferred way of climbing, and in the near future I would like to go open-water swimming. Personal growth can be found anywhere, you just need to look for it.

**FASOCIDE: You created the project “Un mundo con sentido” (A world that makes sense) thanks to your experience. Could you give us some information about it and what its main objectives are?**

Javier: “Un mundo con sentido” is a personal self-improvement project. It is a platform in which you can share your life experiences and your thoughts with other people. The

aim is to break physical and psychological barriers, to raise awareness about deaf-blindness, to avoid stereotypes regarding the disability, to encourage other people to better themselves and to demand the universal right to travel, to do sports and to enjoy nature. Always keeping in mind the two Ss: Self-enjoyment and Spreading the Word.

**FASOCIDE: Do you have any other projects in mind in the medium or long term?**

Javier: For 2020 we have planned some mountaineering activities, perhaps the most striking of which is climbing Mount Kilimanjaro, the highest mountain in Africa. Furthermore, we are intending to create a more social solidarity project, and we are going to do it by organizing two events this year. One of them will be to carry out an activity in support of a foundation with a social cause. The other one will be to help somebody to make his or her dreams come true. This is because the most beautiful thing

about growing and learning is helping others to grow too.

**FASOCIDE: Finally, what message would you like to send to our deafblind youth collective?**

Javier: I am always encouraging people to find their own mountain in their lives.

I encourage everyone to set a goal and to work hard in order to achieve it, always keeping in mind that we may find negative attitudes in our way, but we should have this clear idea: there are people out there, just like you, who do not see barriers and who can help you to reach the sky or to touch the stars.





# Walter Wittich

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Photo:  
Dr. Walter Wittich, Ph.D



We are pleased to highlight the work and achievements of Dr. Walter Wittich, Ph.D., FAAO, CLVT, a pioneer Canadian researcher in support of people with deafblindness.

"I am not visually and/or hearing-impaired, nor am I part of the deafblind community. However, I want to inform people with deafblindness and be informed by them", said Dr. Walter Wittich.

Deafblindness, a combined loss of hearing and vision, affects access to information, communication and mobility. About one percent of Canada's population or approximately 368,400 people are deafblind.

Dr. Wittich is an Assistant Professor at the School of Optometry at the University of Montreal. Coming from a background in age-related vision loss, he now conducts research in dual sensory loss and deafblindness. His research domains include basic sensory science, as well as medical, psychosocial, and rehabilitation approaches to sensory loss.

After retiring from a 15-year career as a professional ballet dancer, Dr. Wittich went back to school to complete his undergrad degree. It was in a methodology course that he met Dr. Olga Overbury, a professor studying age-related vision loss. Their shared sense of humor motivated Dr. Wittich and the two worked closely as she supervised his honors project.

"Following my master's, I became curious about research as a second career... I decided to complete a Ph.D. in Neuroscience at McGill. My thesis was on peripheral vision loss and brain response to peripheral vision loss. I interviewed several individuals with Usher's syndrome, which is characterized by partial or total vision loss and hearing loss that worsens over time. At that point, I felt that I needed to explore hearing loss, so I pursued a postdoctoral fellowship in audiology."

After working as a part-time research coordinator and researcher for two years, Dr. Wittich was hired at the University of Montreal, where he currently is an Assistant Professor at the School of Optometry.

"My research is to improve functional ability, social participation, and quality of life for persons with vision and/or hearing loss. In addition, I am interested in how these combined impairments influence the use of assistive devices, the stigma related to assistive technologies, and the interactions among the device user, the rehabilitation provider, and the device itself," said Dr. Wittich.

Dr. Wittich notes that communication is an important part of the experience in working with individuals with sensory loss. A couple of years ago, he learned American Sign Language (ASL), which he describes as similar to learning choreography in ballet.

"I made a keynote presentation in Winnipeg a few years ago. I signed 'nice to meet you' into the palm of a woman with late onset dual sensory loss. Although I am not a fluent communicator in ASL, it was the first time I was able to introduce myself in this way. It was magical for her as an audience member too."

Dr. Wittich's focus on the rehabilitation of older adults with combined vision and hearing loss has shed light about the contrast of perceptions of sensory loss and the realities.

In Ontario, an estimated 147,736 individuals are deafblind; 22% or 70,080 of Ontario seniors in home care and long-term care reported experiencing vision and hearing loss combined every year for the past three years.

A combined loss of hearing and vision, or the decline of these senses, affects communication and can lead to social isolation. Further, vision or hearing loss increases the risk for dementia in older adults. "There is a lot we can do and learn with respect to dual sensory loss and dementia," said Dr. Wittich.

For those with sensory loss, aging can pose other challenges. For example, in the case of someone that communicates with sign language, the onset of arthritis can create



a barrier. “We must better prepare professionals that work with these individuals... not just interveners, but other health care providers like nurses and even dentists.”

In early 2017, DeafBlind Ontario Services established a collaborative partnership with Dr. Wittich as a Research Affiliate to capitalize on the unique features of deafblind and age-related dual sensory loss communities, support the strategic aims of DeafBlind Ontario Services, and allow creative opportunities to build our research capacity and sustainability.

“I am inspired by the resilience of the people I work with; those impacted by sensory loss and those working in the field... I’ve met so many kind people and I feel that we recognize each other in spirit. I am motivated to continue my research and express the needs of people who are unseen and unheard.”

Dr. Wittich has published 87 peer-reviewed publications, primarily about visual impairment, low vision and dual sensory impairment, bringing much-needed visibility to this

field nationally and internationally. He is a resident researcher at both the CRIR / Centre de réadaptation MAB-Mackay du CIUSSS du Centre-Ouest-de-l’Île-de-Montréal and the CRIR / Institut Nazareth et Louis-Braille du CISSS de la Montérégie-Centre.

We are proud that Dr. Wittich is the co-leader of the Canadian Consortium for Neurodegeneration in Aging (CCNA) Team 17 – focusing on interventions at the Sensory and Cognitive Interface and implications for Communication and Quality of Life – along with a group of eight professionals in the field of vision and hearing from universities across Canada.

At DeafBlind Ontario Services, our commitment to providing a high quality of life for people with deafblindness is ingrained in our values. We are coordinating research into this unique disability, ensuring the evidence is used to enhance services for the people we support and develop partnerships with other community services organizations. Learn more at [deafblindontario.com](http://deafblindontario.com).

# Norimasa Kawasora: life after graduating from high school

People with deafblindness may face various challenges after graduating from high school. I interviewed Nori who is a 28-year-old man with deafblindness from Japan. The interview is focused on his life after graduating from high school.

**Asako: When did you realize that you have visual impairment?**

Nori: When I was a kindergarten pupil, I found that my eyesight was becoming worse than before. I could not read letters in a notebook. My mother also noticed that at the same time. Then she and I saw a doctor. But the doctor told us that I need to have surgery to cure my eyes. Since I did not like to have surgery, I entered the kindergarten for pupils with visual impairment.

**Asako: What about hearing?**

Nori: When I entered the elementary school for children with visual impairment, I wore hearing aids, but I only felt vibrations from people's voices. I did not hear what others were talking about. Although I could understand what my mother and father said to me, I did not understand what others said. My teacher also realized that I did not hear. Then my mother took me to see a doctor.

**Asako: How have you faced yourself as a person with deafblindness?**

Nori: When I realized that I couldn't see well, I did not have any trouble regarding my eyesight. However, when I entered elementary school, my hearing also became worse. Then it continued to decline. It was hard not to be able to hear well. I was especially sad when I did not understand what trainee teachers said.

When I joined the local judo club, I was frustrated because I thought others considered me as just a "deafblind person" since there were no students with disabilities apart from me. When I was a junior high school student, the English class was started. I had English classes with native English teachers. I wanted to listen to their voices so I wore my hearing aids, but I could not hear the teacher's voice. I just felt some vibrations from his sounds. I thought it was a waste of time. After entering high school, I got to know many people with disabilities and without disabilities. I found that there are people with deafblindness besides me.

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### DAILY LIFE AND COMMUNICATION

#### **Asako: How do you spend your days?**

Nori: On weekdays, I go to the office of transition support for employment. I assemble pens and tighten screws at the office. Also, I practice facial massage at a mannequin since I aim to be a manager at a beauty salon. On Mondays, I join the local judo club after work. Also, sometimes I go to university to practice Judo with university students on weekends.

#### **Asako: How do you communicate with the staff members at the office?**

Nori: There is a staff member who can use sign language. Thus, I talk to her with tactile sign language. To talk to the rest of the staff members, I use some simple signs and braille cards. Although I cannot talk with coworkers there, they call staff to assist me when I raise my hand.

#### **Asako: Would you like to communicate with your coworkers?**

Nori: I want to communicate with them. But we take about 10 minutes' breaks, so it is too short to chat with them. When people talk with each other, I feel anxious if they are

talking about me. I want some chances for us to interact.

#### **Asako: Who do you usually communicate with? And how?**

Nori: I usually talk with my mother and sister using tactile sign language. So they interpret what the rest of my family members are talking about. Also, my niece sometimes uses simple sign language, such as "Thank you" and "Hello". Besides my family, the interpreter-guide uses tactile sign language for me. I also use finger braille when I talk to a person who can use it.

#### **Asako: What communication method is the best for you?**

Nori: For receiving, tactile sign language is easy for me. For expressing, sign language is the best when I talk to a person with hearing impairment. But when I talk to a person who uses finger braille, I can also use it. In my opinion, finger braille is good in cases when I cannot move my elbows or when I talk in a quiet room. But I prefer talking in tactile sign language rather than finger braille.

### LEISURE TIME

#### **Asako: When did you start to play judo?**

Nori: I started to play Judo when I was a fifth-grade primary school student. At that time, I did not like wearing a Judo uniform and playing judo because it was painful when I was thrown by an opponent. I heard that my class teacher and vice-president of my school found that Judo was suitable for me. When I learned Judo with a very strict teacher, it was too tough. However, when I was a junior high school student, I got a medal at a championship. I was relieved when I got the medal because I had worked very hard. I also

thought that I wanted to tell my experience to many children. Also, I got a bronze medal at the junior world judo championships in Hungary when I was a high school student. It was a great opportunity for me to meet many Judo players from all over the world. What surprised me was that there was a French player with deafblindness. We could not communicate with each other easily because we spoke different languages. However, finally, I could communicate with them with help from the interpreter-guide. Then some players gave me hugs. The hugs made me happy from the bottom of my heart.

### INDEPENDENT LIVING AND WORK

#### **Asako: What have you done after graduating from high school?**

Nori: I entered the national rehabilitation center after graduating from high school

for a year to try to live without my family. I learned cooking and cleaning my room, received training in orientation and mobility, and so on. I also shared information with

other people with disabilities. In the last six months, I joined the model project for people with deafblindness and lived with several people with deafblindness. A surprising thing was that an interpreter-guide was assigned to work with me from morning to 9 pm.

**Asako: Do you think the experience is useful for your life?**

Nori: I think the experience in the center is useful for my life because now I can not only cup noodles but also healthy food. I already learned how to cook potato salad in high school. I can look after myself.

**Asako: Do you remember what you learned at school besides potato salad?**

Nori: I learned how to cook yakisoba and edamame tofu. I also learned how to use a sewing machine and a clothes iron. Using a clothes iron is very useful to press shirts although it is very hot.

**Asako: What did you do after training in the rehabilitation center?**

Nori: I worked at a community workshop for five years. There were many people with multiple disabilities, including people with deafblindness. I would often pack my bag, a staff member would pick me up before work and drop me off after work. I enjoyed working in the community workshop, but the salary was low. So I wanted to work at a general company.

**Asako: Then you moved to Osaka, right?**

Nori: Yes, I entered another community workshop that specializes in deafblindness. It has a group home, so I stayed there. However, the salary was still low for me. Besides, some of the requirements did not suit me. Thus, I quit it and went back to Hiroshima. After that, I started to go to the office of transition support for employment as I said.

**Asako: What did you want to be when you were a child?**

Nori: I wanted to be a police officer because I thought I could protect my family that way. When I was a student, some policemen visited our school for an evacuation drill. I learned about the job of policemen. When I interacted with them, I thought that their uniform and salute were so cool.

**Asako: Why did you give up the dream of being a police officer?**

Nori: I found that being a police officer is a dangerous job. If I am shot by someone, I will die. Also, policemen need to “see” and find out if a person is suspicious or not. It is difficult and dangerous. Therefore, I gave up aiming to be a police officer.

**Asako: What kind of job have you aimed for after high school?**

Nori: I wanted to be a housekeeper in a hotel because I thought it sounded fun. Thus, I asked staff at hotels if I could work there, but the staff told me that it was impossible to be a housekeeper because I cannot see a hair. For me, getting a job that I can do is more important than getting a job that I want to do. And I feel uncomfortable when people consider that a particular job is impossible for me to do because of my eyesight. I want to find a good job which I want to do and I can do in the future.

**Asako: How do you look back on your 20s?**

Nori: I have made several mistakes after graduating from high school. First, there were a lot of obscure points in my future plan. I had consulted with some high school teachers, but I could not find what I could do. Second, I found the salary at the community workshop was low. Although I listened when I was told how much I would get, I realized how little it was for me only after getting my first paycheck. Also, I did my best at the workshop for more than three years. Third, I did not understand some of the clauses of my contract with the group home in Osaka. However, I consulted with some high school teachers and decided to leave the group home.

**Asako: Is there anything you want to tell readers?**

Nori: I want to share my thoughts with people with deafblindness all over the world. I want us to think about your troubles, challenges, and problems together. Also, I want to interact with young people. I want to know how they have overcome unpleasant, sad and bad experiences. I am not good at speaking English, but I want to keep and construct peaceful relationships between Japan and all countries. I wish you peace and happiness.

# National Strategic Working Groups in Latin America.

## Adding a layer of impact beyond the school setting and into society

KARINA MEDINA

GLORIA  
RODRÍGUEZ-GIL

MARTA ELENA  
RAMÍREZ

AND

ANA LUCIA RAGO

### Introduction

Perkins International in Latin America (PILA&C) from Perkins School for the Blind envisioned a concept of convening a diverse group of individuals and leaders representing various organizations from the government and civil society with the purpose of together designing national or regional plans to improve the quality of education for children with blindness and multiple disabilities. We called them National Strategic Working Groups (SWGs). These groups would not only include educators from public and non-profit schools and ministries or secretaries of education, but also educators from higher education institutions, individuals with disabilities, mothers of individuals with disabilities, representatives of human rights organizations, donors, representatives from the medical and rehabilitation field. It was a space for strategic thinking, leadership and planning; and its purpose was to make achievable systemic changes.

PILA&C convened three groups, one in each of the three countries we are currently working in Latin America with funds from a U.S. foundation: México, Brazil and Argentina. The composition of each group varies depending on the historic leadership of Perkins in the country and the connections built, the relevance of the organization in the country, and the disposition of organizations and their representatives to actively participate.

The initial proposal to the groups was based on four main axes defined by PILA&C's experience of working in the region for almost 30 years. These axes were:

- Teacher training, the need to enhance the teacher training programs and other related degrees by including content related to the education of students with multiple disabilities and visual impairments, including those with deafblindness (MDVIDB).



- The role and status of special education schools in the education of students with MDVI DB as well as the support they provide or should provide to inclusive state-run and private-run schools in regard to this population.
- The present and future situation of students with MDVIDB. Based on the previous axis, this axis focuses on the needs of the students in regard to enrollment, permanence and graduation, the access to a general education curriculum, the programs that prepare them to life after school, the importance of collaboration between the school and the home and the exclusion of this population from the system.

- Articulation between health and education, detection, referral of children and young individuals with MDVI DB to the educational system.

PILA&C invited members to discuss the proposed axes, asked to suggest modifications, and then list priorities and draft an action plan. These priorities were aligned with the national situation of each country, the national laws and the 2030 UN Sustainable Development Goals. The process of creating the action plan responded to specific achievable country needs, what was possible, the countries' interests, and the time each member had available to dedicate to the plan proposed.

### The geography and composition of SWGs



**Fig. 1.** The SWGs are in the three largest countries in Latin America

## EXCHANGE OF EXPERIENCE

The members of each SWG represent:

- Secretaries or ministries of education (national, state and municipal level)
- Universities and other higher education teacher training institutions
- Disability advocacy groups and human rights organizations
- Individuals with disabilities
- Regular and special education schools
- Health/rehabilitation services
- Donors.

**SWG members are located in the following states/provinces:**



**Fig. 2. MÉXICO**



**Fig. 3. BRAZIL**



**Fig. 4. ARGENTINA**

## The SWGs' action plans so far

The México SWG was formed in 2019 and has held three meetings so far: two in person and the third and the last one a combination of an in-person and online meeting. The Brazil SWG has held four meetings: two in 2018 and two in 2019, and the Argentina SWG has held two meetings in person in 2019. In 2020 each group will meet at least two more times as they continue to refine their action

plans and implement them. Each plan has defined actions, a timeline and responsible people who are divided into subgroups.

With regards to the analyzed axes, Teacher training, The role and status of special education schools, The present and future situation of students with MDVIDB, Articulation between health and education, the following actions have been proposed by each SWG:

### México SWG actions:

## Teacher training

- Create a brief to present to a teacher training program so they include in their training curriculum a course on the education of students with multiple disabilities.

## The role and status of special education schools

- Design a strategy to promote interaction between families and schools and between families with a focus on adaptive skills and communication. Disseminate this strategy in Mexico's public special education schools as a model for working with families.

### The present and future situation of students with MDVIDB

- Create a virtual magazine at the Autonomous University of Mexico (UNAM) to sensitize the university community and society about the support required by people with MDVIDB.
- Make and disseminate small videos in order to sensitize society on matters of physical accessibility such as wheelchairs, ramps, railings, augmentative and alternative communication; educational strategies for training teachers with a human rights approach to people with disabilities.

### Brazil SWG actions:

#### Teacher training

- Create a virtual library accessible for all with resources in Portuguese, including master's dissertations and doctoral theses that hardly reach the educators who are at school on a daily basis with children.
- Identify appropriate diagnostic evaluations tools for children with MDVI to suggest to the MOE/Secretariats of Education so we can standardize the evaluations and train educators and schools to use them properly.

### Argentina SWG actions:

#### Teacher training

- Incorporate curricular spaces regarding disability/MDVIDB in higher education, university and non-university careers.

### Articulation between health and education

- Create a national directory of health services for people with MDVIDB.
- Create a national directory of educational services for people with MDVIDB.
- Validate an instrument for diagnosing neurological risk that is being developed by a medical doctor who is member of the SWG.
- Prepare and distribute three infographics on care for people with MDVIDB:
- Right to timely care (for pregnant mothers)
- Timely care as a duty (for doctors)
- Full care approach (for families for people with disabilities).

### Present and future situation of students with MDVIDB

- Write a document and present it to the federal ministry of education on the current situation with the education of children with MDVIDB in Brazil in areas such as: deficiencies in teacher training programs; understanding the role of specialized educational support teachers for children with MDVIDB included in regular schools; and the use of financial resources to purchase materials and other items to meet the needs of students with MDVIDB.
- Promote social actions (both small and large) that help parents understand and advocate for their children with MDVI and promote the awareness of society.
- Support the development of quality services both in education and in the rehabilitation area.
  - Organize a regional meeting of higher education institutions for training in education and health or rehabilitation

to raise awareness about the importance of training in multiple disabilities.

- Propose that the representatives of the Disability Subcommittee of the Council of Rectors of Universities, at the national level, consider the importance of training and raising awareness of future professionals, graduates of these institutions, in relation to people with disabilities, with the incorporation of a curricular space that allows them to orient their actions to respond to the needs of this particular group with their services.

### **The role and status of special education schools**

- Prepare tutorials on good practice experiences, taking the actions carried out with the model programs that are being implemented at the national level and whose experiences and institutional improvements can help other services.

### **What we have learned and conclusions**

The formation of the SWGs has revealed a need to bring a diverse group together to discuss and plan matters related to the education, health, human rights and mobilization of resources for children with disabilities. It has also confirmed the importance of bringing leaders from areas outside of education, as what we want to accomplish is complex in nature and we want to make the population with MDVIDB visible to other spheres of society.

The expertise exists in these countries and the willingness of these leaders to make a change is evident. What is clear to PILA&C is that we are bringing out the voice of children and youth with MDVIDB and their families and, where people are already aware of the needs of this population, we are supporting what they are trying to create in their countries.

### **The present and future situation of students with MDVIDB**

- Write and present to the legislature a note in support of the bill S-3/19. The purpose of the law is to specifically include multiple disabilities and deafblindness as separate concepts in the definitions of disability and in the description of its different categories.

### **Articulation between health and education**

- Make the number of people with disabilities in vulnerable situations visible, including people with MDVIDB, and identify service needs, using accurate data obtained from the national census.
- Develop categories within a statistical data collection tool that allows better identification of people with disabilities in general and people with MDVIDB for the national census in Argentina.

One of the challenges that each strategic group faces is related to the impact that it wants to achieve at the national level and the transformation in culture and attitudes, practices and policies that is needed to build a more inclusive and just society. To achieve that, the strategic groups must develop skills that allow fluid communication about activities and their results. This, in turn, requires permanent commitment which can be a challenge when stakeholders have multiple commitments and/or are public officials who may change with the next change of government.

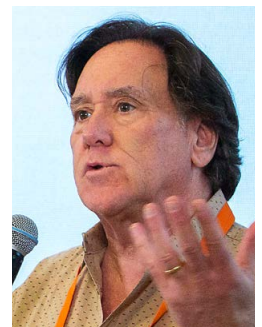
We are just beginning. Together we are learning how to work better together, refining the ideas behind groups and finding the best ways to execute them. We know that only together we can bring change.

# Developing a global community of emerging scholars

A focus on engaging individuals with deafblindness and their families in research initiatives

The Deaf-Blind Support Foundation «Con-nection» is a Russian National charitable organization dedicated to meeting the needs of deafblind people. In 2018 and 2019, this organization collaborated with Deafblind International (DbI), sponsored the first and second International Young Researchers Conference on Deafblindness.

This international conference included both seasoned and newly engaged researchers in the field of deafblindness and resulted in establishing the beginning of a global community of young and newly engaged research professional. As a result, the concept of an on-going global community of emerging scholars was initiated.



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During the November 2019 conference, newly engaged researchers from Europe, Asia, Americas, and Russia gathered in Saint Petersburg to share their interests

and participate in professional development from highly recognized experts. In addition, young adults with deafblindness joined the conference to engage in workshop



## ■ EXCHANGE OF EXPERIENCE

activities for the purpose of adhering to the widely recognized concept, “Nothing About Us, Without Us” (Latin: “Nihil de nobis, sine nobis”). The youth with deafblindness were engaged in meaningful ways to provide an authentic voice to the developing research initiatives and to enhance the growing community of young researchers from around the world. Although a formal organizational structure remains in its infancy, the 2018 and

2019 conferences have initiated the creation of the first Global Community of Emerging Scholars in Deafblindness. This community that reflects an international group of young scholars who are newly engaged or interested in the field of deafblindness will evolve to replenish the needed evidence for new practices in supporting the development, habilitation, and education of individuals who are deafblind from all over the world.



During the 2019 Conference, emerging / young researchers in collaboration with their deafblind peers were divided into five categories that represented their individual research interests that included (1) communication; (2) new advances in medical research; (3) education & assessment; (4) family & social services; and (5) arts & sports. Conference participants worked in teams to identify a variety of areas of inquiry across these themes. The result was a collection of refined areas of needed research such as identifying the parameters of deafblindness (definition), exploring the notion of a deafblind identity, minor language status among people who are deafblind, and practices supporting quality of life (including employment). As seasoned researchers facilitated the teams in discussions and debates, it was evident that there are global areas of need influenced by individual

countries and their cultures. At the end, teams generated possible research questions that could be addressed by formulating cross-cultural initiatives.

As a by-product of these two annual conferences, the formidable task of establishing a global community of young/emerging scientists has been initiated. The foundation in which to continue building this professional learning community has been solidified and partnerships have been seeded among peers, as well as seasoned scientists in the field. Unfortunately, we are inhibited and preoccupied by the serious nature of the COVID-19 virus, which is influencing the time and energy of all citizens of the world. However, it is without doubt that the efforts made and the partnerships that have been formed will resume the on-going development of

this Global Community of Young / Emerging Researchers. Dbl and its partner organizations are committed to continue their efforts to facilitate forums that encourage professionals from around the world to collaborate

on new research studies; share research ideas and accomplishments; and provide access to the advice and support from its membership including maintaining a prominent role for individuals with deafblindness.



If you are interested in participating in future initiatives for emerging researchers in the field of deafblindness, please complete this on-line survey. <https://www.surveymonkey.com/r/W5WTFNW> or the QR Code below.





# Lessons on deafblindness from research in East Africa

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Sense International (SI) is committed to undertaking research so we can better understand the contexts that we work in, the complexity of deafblindness and multi-sensory impairments (MSI) and what works best to overcome the challenges facing people with complex disabilities. With this in mind, SI has recently carried out three different research projects in Tanzania, Kenya and Uganda.



## The Teaching Assistant Model in Tanzania

Funded by the Human Development Innovation Fund, SI Tanzania launched an inclusive education project that sought to demonstrate to the Government of Tanzania that children with deafblindness/MSI can successfully be included in mainstream schools in Tanzania by using SI's two-step model:

**Step 1:** Using a specialist curriculum, children prepare for school through home-based education that is provided by parents and supported by teachers.

**Step 2:** Children with deafblindness/MSI are included in mainstream classrooms with the support of teaching assistants (TAs). Parents, teachers and TAs are trained on inclusive education and techniques for teaching children with deafblindness/MSI.

SI carried out research to establish the impact of the approach. Findings showed that TAs play a dynamic role towards achieving inclusive education for children with deafblindness/MSI by: providing one-on-one

educational support, 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.

The research provided recommendations to maximize the potential of the TA model. Institution-based recommendations included strengthening policy to better incorporate TAs into the education system, scaling up the TA model across the country, increasing financial commitment by the government and ensuring learners have individual learning plans. Attitudinal recommendations included facilitating greater community-based sensitization to increase the awareness of the potential for all children to be educated in mainstream classrooms and the continued need for teacher and TA training on inclusive education. Finally, environmental recommendations include ensuring new and existing education buildings are made physically accessible for all.

## Social, economic and political inclusion of youth in Nairobi

SI Kenya carried out research to examine the extent of social, economic and political inclusion of youth with disabilities in Nairobi County, using participatory action research to collect primary data in addition to a systematic literature review. The research produced several interesting findings. The study showed that many programs that aim to increase employment levels among youth with disabilities are ineffective and do not result in economic independence. The study also demonstrated that most youth with disabilities are unaware of existing social protection mechanisms and financial resources for initiatives are lacking.

The research indicated that young women with disabilities are “doubly” discriminated against, on account of both their gender and their disability. Young people involved in the study identified the high risk of sexual

and gender-based violence experienced by women and girls with disabilities as a barrier to achieving equality and inclusion. Finally, young people with disabilities identified numerous barriers linked to pursuing romantic or sexual relationships due to the prevalence of negative socio-cultural beliefs and myths about their ability to have sex or have a family. The research demonstrated that the barriers facing young people in Nairobi are multi-faceted, so solutions must also be interdisciplinary and transformative if change is to be achieved.

This research supports advocacy by SI Kenya with government authorities in order to ensure more support for people with disabilities in line with the Sustainable Development Goals and the UN Convention on the Rights of Persons with Disabilities.

### The cost of caring for a child with deafblindness/MSI in Uganda

SI Uganda commissioned a study on the economic impact of caring for a child with deafblindness/MSI. Data was collected from five districts including Kumi, Jinja, Pader, Luwero and Kampala and from 62 participants through interviews and focus group discussions.

The research findings demonstrated that the cost of caring for a child with deafblindness/MSI is comparatively higher than caring for a child without a disability for a plethora of reasons. The increased need for specialized medical and educational support is costly. Furthermore, the research found that households with a child with deafblindness/MSI are more financially vulnerable as a result of an increased prevalence of spouses (especially fathers) leaving the home after the diagnosis. The findings conveyed that the economic impact of caring for a child with deafblindness/MSI is twofold. Not

only are costs increased as a result of the need for specialized services and support but furthermore, the productive capacity of the household is weakened by the common departure of fathers. Additionally, the huge time commitments associated with caring for a child with deafblindness/MSI means many caregivers have no time to carry out any form of income-generating activity or to maintain steady employment. Finally, caregivers of children with disabilities are also often discriminated against as a result of local beliefs resulting in marginalization from employment or trade.

The research underpins advocacy to the government of Uganda, by SI Uganda and the Ugandan Parents of Deafblind Children Association, for increased social protection for families with children with deafblindness.

Contact: [info@senseinternational.org.uk](mailto:info@senseinternational.org.uk) for more information.



# Winter School on the basics of psychological and educational support in Moscow

Each year the Resource Center Supporting the Deafblind and Their Family Members “Yaseneva Polyana” organizes a Winter School for young people with dual sensory impairment and specialists working with children and adults having special needs in different Russian regions.



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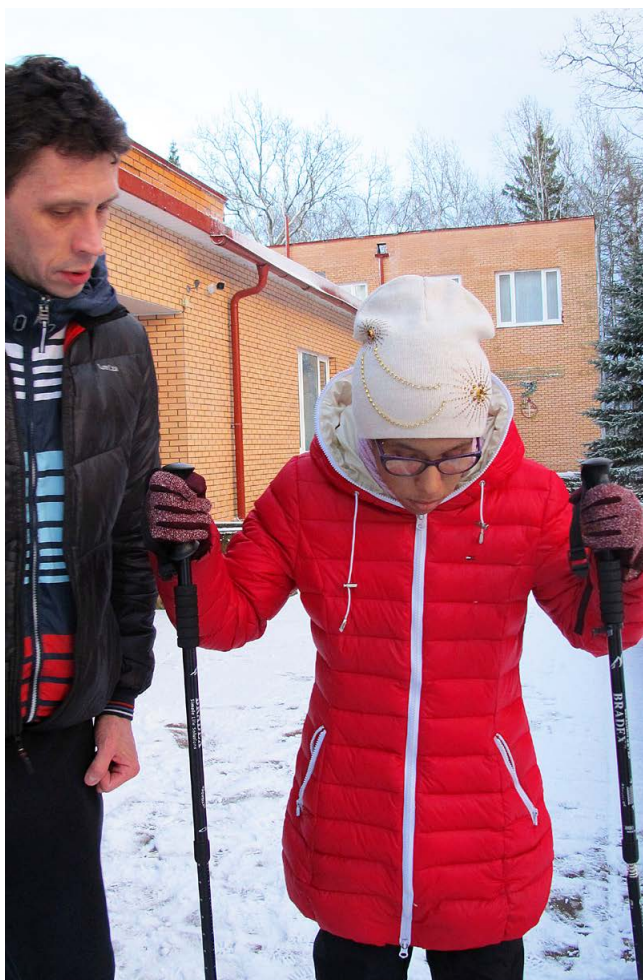
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## ■ EXCHANGE OF EXPERIENCE

This event includes two parallel programs. One of them is the intensive training for teachers from different regions of Russia. These are eight days of lectures, discussions and practical exercises, where they study the issues of deafblindness.

The second part is a camp for young people with dual sensory impairment. The organization of this event requires consideration of many details and aspects.

Firstly, the choice of venue. It should be convenient for living and orientation in the building space for participants and their attendants, it should have a gym and a swimming pool, and the area around should be convenient for winter sports.



Secondly, the selection of volunteers who will accompany each participant. They are usually young people, students of pedagogical or psychological universities. Most of them have been trained to guide people with

deafblindness and have special means of communication with them. We try to select volunteers individually for each participant, taking into account not only skills, but also some character features and interests.

Thirdly, participants themselves. For four years, we have invited quite independent young people. Before the camp started, we had to make sure that they would be able to live in a room on their own, navigate the class schedule and inform their attendants of any problems with the help of either verbal speech or sign language.



The main goal of the camp is to provide young people with an independent life experience without the constant help of family members, to discuss their ideas of an adult independent life and to develop some skills necessary for it.

The training program includes adaptive physical culture in the gym, in the pool and outdoors, individual psychological counseling, various workshops and group communication training aimed at developing the ability to express own one's thoughts and listen to others.





The most recent camp in 2020 was different. For the first time, we invited young people with more difficult developmental conditions who found themselves in a situation of living without parents for the first time...

It was definitely a challenge for the families of young people. For the parents it was not an easy decision to let their son or daughter live without them for several days. There were many worries: would he or she be safe in the new environment? Would other people be respectful of their needs, could their son or daughter manage their behavior around new people? All eight young people who had participated in the Winter School this time had not only sight and hearing loss, but also additional disabilities such as cerebral palsy, autistic spectrum disorders, intellectual disability, epilepsy, and many of them had challenging behavior.

Each one of the participants has a unique character, bright individuality and also strict preferences, likes and dislikes, as well as a

unique way of getting information about the world and communicating with others.

To make the participants and the team members comfortable with each other, a passport was made for each participant. It included information on how the participant sees and hears, what means of communication he or she uses and what means of communication he or she understands. The passport also described behavioral challenges that can occur, sleeping habits, the list of required medications and other important information, such as whether a person should be watched closely to prevent falling because of bone fragility. That information was provided by parents.

This helped volunteer attendants and other specialists to get acquainted with the participants and feel more confident at the start.

For participants, each day of the Winter School was a step to new communications and friendship; each day was challenging

because they had to leave behind some of their old routines and habits and make more and more choices, do a lot of new things on their own.

It was a huge progress in communication for these young people because most of them communicated with other people (other than family members or teachers) for the first time in their life.

Within the group, there were varying levels of independence. For some participants it was great progress to eat by themselves, while for others it was to get up on time in the morning. One way or another, everyone obtained valuable living skills.

There were some challenges for professionals, too. How to encourage independence? How to see the person you are taking care of as an adult and not a child? How not to be overprotective? Where is the line that marks off private space and how to respect

it? These are the questions that were often discussed during this Winter School.

This time participants did not only have communication training, but also vocational training, where they could learn how to make things that can be useful as a gift or a commodity such as candles, soap or snacks with dried fruits.

Two months after finishing the School, we asked parents what changes they had noticed in their sons' and daughters' behavior and what that camp had meant for them.

Almost every parent said that his or her child became more independent in some way. They try to make their own decisions, or make more plans, or get dressed all by themselves if they are coming out. One mother said that this Winter School gave her a hope that her son could live independently one day, with the help of people other than his mother.

# Trip to Indonesia

In April 2019 I was fortunate enough to be invited to Indonesia by IDWA (the Indonesian Deaf Welfare Association) on a mission to work with and educate a group of 10 deafblind people from around the country. This came out of a wide-scale lack of acknowledgement of deafblindness amongst professionals, the needs of deafblind people themselves and a wish to learn more about the condition.

I am a well-versed trainer and I have an established training course which I have used for many years across mainland Britain and is devised largely to inform and educate what deafblindness is, focusing on Usher syndrome. My established program is also aimed at families, practice professionals and the deafblind community to help them best deal with their

conditions and get the most from life. Upon my arrival, I quickly discovered a whole host of issues which meant my well-established training course had to be quickly rejigged and amended to a whole different level. I adapted it to best match the brief requested by IDWA and included more generic and internationally appropriate information.

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What was most startling was that a majority of the participants had never met another deafblind person before, and many believed that they were the only deafblind person in the whole wide world. I can only imagine how shocking and isolating that would feel.

In my group of deafblind people, I quickly discovered no less than 15 unique types of communication including Basindo, ADPD, ASL, clear/loud speech, lip reading, as well

as technology being relayed via voice recognition software and paired phones. This entailed some massive challenges in terms of me presenting to the group and communicating directly and indirectly with people.

My planned group activities were a challenge, and I found myself on a permanent mission to match people who would be able to communicate with each other due to a lack of communication support. The aim behind the activities was to address issues in deafblindness as well as opening the group up to new challenges of observing and learning to communicate in a new and different way, so grouping the right people and communication methods was crucial.

I was fortunate, and grateful, to have a group of supporters from the local Deaf and hearing community to act as guides and sighted assistants to the deafblind people. I discovered (by observation) that communicator guide training was much needed as it had never been delivered before. I was able to run an afternoon session to explain in detail the empowering role of the communicator guide and how important they are in making the world meaningful to deafblind people.



Over 90% of the population in Indonesia are Muslim, but neither Islam nor the other religions are made accessible to Deaf, blind and deafblind people. Indonesia is a very tactile-adverse culture where touch and social haptics are not socially acceptable. This needs radical change to meet the communication needs of deafblind people.

I was able to facilitate an evening workshop for sign language interpreters from across the country who largely operate in isolation. Sadly, there is no recognition of their status as professionals, no official training program, qualification system, registration body or even a code of ethics or a peer support network. Having addressed these areas, the interpreters will look to ensure progress in the future by partnering with more advanced countries in Europe.

I was invited to address three formal conferences during my time in Jakarta on the needs of deafblind people from a UK/European

perspective. I presented to the president's special advisor on disability on disability issues; two ministerial advisors: Health and Women's Rights / Child Protection and also the Minister of Social Affairs for Java Island. Remarkably, none of them had heard of the concept of deafblindness as a unique disability. They openly admitted to having no service provisions for deafblind people across the country. They also had a rude awakening of where the Indonesian world stood on the issues relating to people with disabilities and the lack of legislation to protect and uphold people's rights.

On reflection, my 12 days working in Jakarta were both a challenge and an eye opener to the huge amount of work to be done. Fortunately, there is a certain amount of enthusiasm to move forward with this work and IDWA are receptive to international partners whom they can work with and learn from.







I am very pleased and elated to hear that there is a new Indonesian deafblind group which has been recently set up by a deafblind man, Chandra.

If you need any more information, please do contact me at [emma.boswell@sense.org.uk](mailto:emma.boswell@sense.org.uk).

# Brecht theater techniques shaping the award-winning deafblind theater group

Since its formation in 2014, Drama Express has established itself as both a specialist and innovative youth theater program. The members of Drama Express have sensory impairments with a high percentage of those deafblind. The group is located throughout the southern counties of the UK, in particular areas where young deafblind people are isolated from their peers. Developing friendships is a key aim of Drama Express and the positive sharing experience of drama provides that opportunity.

**SIMON ALLISON**

DBI YOUTH  
NETWORK



## ■ EXCHANGE OF EXPERIENCE

The group celebrated its most successful year in 2019 receiving numerous awards including the Queens Award for Outstanding Voluntary Service at Buckingham Palace. Drama Express also achieved recognition through the National Arts epic awards

program for breaking down barriers in the community.

Drama Express has taken deafblind youth theater out into local communities demonstrating that theater can be accessible to everyone including those who perform on stage.



A key factor in the diversity of Drama Express is the use of techniques developed by the pioneering playwright Berthold Brecht. One such technique is the use of narration. The narrator has a multi-faceted role, telling the story, directing the action, prompting stage management and delivering factual information. In Drama Express productions, the narrator is crucial to those supporting the deafblind actors on stage as they use their intervention skills to guide the actor through the performance.

Another Brecht technique is a very limited stage set and minimal use of props. For the actors in Drama Express, a non-cluttered

environment ensures both successful and safe navigation around the stage. The layout of both scenery and props can be used as reference points for the actors positioning themselves for each scene. Constant scenery changes and too many props can become both confusing and misleading.

Brecht featured the use of monologues in many of his productions. This is also a common theme of Drama Express productions used to “step out” of the main production. The use of monologue techniques gives the opportunity for the actors to voice their own views, opinions and personal stories. Monologues have been delivered through



the use of BSL, deafblind manual and “hands on” signing. Monologue themes have included “If I ruled the world” and “My life story in five minutes”.

Finally, Brecht was a great advocate of surrealism and in particular surrealist humor. Thinking “outside the box” enables the actors in Drama Express to explore their own creativity and have an input into stage productions. The life experiences of those with deafblindness are often different through the very nature of how the world is accessed. Transferring these experiences onto the stage gives an added dimension to creativity. When humor is added, the audience can reflect that deafblind people often have a positive and uplifting approach to life.

Simon Allison, coordinator of the Dbl Youth Network and also the founder and charity

director of Drama Express, explains how Brecht techniques have become the template for the success of Drama Express.

“For each Drama Express production, we are constantly thinking about engagement and inclusion of ALL the actors. Our membership is around 35 young people with a diverse range of sensory needs. In following each Brecht technique, our productions have the scope to adapt and meet all the actors’ needs. There is as much skill involved in the planning and preparation as in the delivery of a performance.”

2020 is already looking positive for Drama Express, with several commissions and theater venues requesting return performances. Everyone in Drama Express, especially the young actors, should feel very proud of their achievements.

# *In Touch*: more than a theatrical performance

CENTER FOR THE  
IMPLEMENTATION  
OF CREATIVE  
PROJECTS  
«INCLUSION»

In the spring of 2020, it was announced that Italy would see *In Touch*, the only theatrical production in the world that includes people with deafblindness and sighted and hearing people. Owing to the coronavirus pandemic, however, the Russian-Italian version has been put off until fall. The play premiered six years ago and has seen over 50 performances since, featuring many renowned actors from Russia and other countries, as well as people with deafblindness from around the world. This unique theatrical experiment still sells out concert halls and challenges people's ideas of what it is like to live without hearing or sight.

*In Touch* is a joint production of the Deaf-Blind Support Foundation "Con-nection" and the Theatre of Nations. "Five years ago we decided to make this performance to educate society about deafblind people. We thought that theater was the simplest and most accessible way of reaching people's hearts," says Dmitry Polikanov, the first president of Con-nection. "Besides, many of our beneficiaries had great creative potential, so we wanted to involve them in this process and give them the opportunity to acquire new skills and express themselves on stage."

The idea to make a play about the lives of deafblind people belonged to Yevgeny Mironov, an award-winning Russian artist and artistic director of the Theatre of Nations. The first version of the play involved such celebrities

as Ingeborga Dapkunaite, Egor Beroev, Elena Morozova, Olga Lapshina, Oleg Savtsov, Ilona Gaishun, Yulia Khamitova, Ekaterina Sakhno, Kirill Byrkin and Rustam Akhmadiyev, as well as seven deafblind people, beneficiaries of the Con-nection Foundation. Most of them continue to be involved with the production.

The project grew out of actual stories of life and struggle, despair and overcoming, love and joy experienced by deafblind people. Taking their interviews as the basic material, playwright Marina Krapivina created a dramatic work exploring the relationship between two worlds: the world of people with deafblindness and the world of sighted and hearing people. The characters of the play are a very diverse crowd: they come from different generations and

backgrounds, they have different circumstances and world view. Key to the play are the life stories of Olga Skorokhodova, the first Soviet deafblind scientist known as the

Russian Helen Keller, and Alexander Suvorov, Doctor of Advanced Studies in Psychology, who was played by himself in the original version of the production.

### One's own voice

The play premiered at the Small Stage of the Theatre of Nations on April 19, 2015, and then went on to conquer other important venues of Moscow and St. Petersburg. But the issue of deafblindness is a universal one, and in 2017, the creative team decided to make an international version of *In Touch*.

The new version was prepared with the help of Jenny Sealey, co-author of the opening ceremony of the 14th Summer Paralympic Games in London and artistic director of the Graeae Theatre Company (UK). Jenny brought a fresh vision to the stage: she changed the play by making the deafblind characters much more independent and by minimizing the differences between all those involved in the production, irrespective of their professional level or physical handicaps. Now both deafblind and sighted and hearing actors could tell their stories from an independent stance, enabling a powerful and equal cooperation between the two worlds.

The production also changed its emotional tone. "The original version was dominated

by themes of fear, isolation, suffering and helplessness. In the new version, there was a desire to paint a brighter picture with stories of active living and creative effort, of the actors' travel, dreams and adventures. They would tell you new episodes from their lives, dealing with motherhood, politics, inequality, outer space, esotericism, observations made on the subway, and lots of other things. The themes of family and love came to be materialized in the play," says assistant director Larisa Nikitina.

The producers found new ways of tactile communication to maximize the actors' capacity to move around the stage and to make them independent and equal participants of the performance. A system of tactile signals was developed that is invisible to the audience but clearly understandable to deafblind actors, much like verbal lines in a play. "We managed to create this space where we are all equal. It is a common path where we learn from each other and respect each other," says Jenny Sealey.

### A variety of languages

The new version of *In Touch* premiered at the Royal National Theatre in London in October 2017, which heralded the start of a new, international era for the production. The London performance involved the Russian actor Yevgeny Mironov and the British actress Jenny Agutter, but the highlight of the cast was Raji Gopalakrishnan, a deafblind actress from the United Kingdom. Then a French version of the play was performed at the United Nations offices in Paris, extended to include the story of the French deafblind teacher Marie Heurtin, told by Jane Constance, winner of *The Voice Kids*. Excerpts from the diaries and poems of Olga Skorokhodova were read by the famous Russian actress Chulpan

Khamatova. The play also featured Amelie Armand, an actress from France.

A year later, the team presented a Russian-Dutch version of the play, integrating the well-known Dutch deafblind athlete Michel Tilbeke. His story is an example of amazing resilience, perseverance and love of life. Another new star was actress and singer Dagmar Slagmolen, who took part in every performance of this version (Amsterdam, Hertogenbosch, Brussels), telling the story of the American deafblind icon Helen Keller.

In 2020, the production will learn to speak Italian, as the Italian deafblind lawyer Mercurio, president of the Italian committee of deafblind

people Lega del Filo d'Oro, will enter the stage along with the permanent Russian troupe. Also performing will be professional artists from Italy. Traditionally, the new version will premiere in Moscow before going to Milan. The tour will be supported by the well-known Russian charity foundation Art, Science and Sport, the Italian Cultural Institute and a number of other organizations.

*In Touch* remains the only production of its kind, involving deafblind and sighted and hearing actors on equal terms. "This performance makes a change in the life of every member of the audience. The ideas that we used to have of what deafblind people and people with disabilities are capable of, these ideas are now changing, and the attitude towards them is changing," says Tatyana Medyukh, development director of the Inclusion Center for Creative Projects.

Indeed, the audience always receives this production very warmly. The play has also

been nominated for various professional theatrical and public prizes, and theater experts have included it in the list of the best inclusive documentary productions. One of the important goals of the play is to draw attention to the need for a full integration of deafblind people in society.

*In Touch* has become a rallying point for organizations and deafblind people in different countries, helping them to find each other and share experiences, make friends and communicate. An important initiative in this regard is the project Theater without Borders carried out by the Inclusion Center for Creative Projects, which was established by the Con-nection Foundation to promote inclusive theater. In addition to inviting deafblind people from different countries to take part in theatrical performances, the project also envisages educational events, seminars, guided tours and exhibitions.

### Background:

#### Theater for all

After the first success of *In Touch*, it became clear that theater can be a very powerful means of rehabilitation and socialization for people with disabilities, as well as a way to change the attitude of society towards those who are "different". That is why the Deaf-Blind Support Foundation "Con-nection" created the Inclusion Center for Creative Projects, which is engaged in systematic work to develop inclusive theater in Russia, creating performances, providing inclusive theater education for deafblind people and people with other types of disabilities and working to change public opinion about people with disabilities. Today the Inclusion Center already has 15 inclusive performances in its repertoire. Its Theatrical Inclusion Schools are active throughout Russia. More than 80 actors with disabilities – students and school leavers – go on stage to convey one simple thought to their audiences: disability is nothing more than a unique characteristic that does not prevent you from living, loving and creating.



Deafblind people from Russia, permanent troupe members of *In Touch*

## Irina Povolotskaya



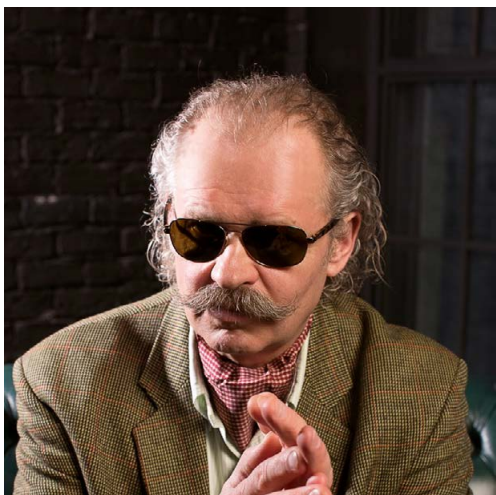
Irina is a deafblind actress, writer, artist, psychologist, member of the Union of Writers and the Union of Journalists of Russia. Her creative alias is Violet Fairy Phoenix. Irina has written poetry and prose, starred in documentaries and short films, written columns and done painting. She is involved in several performances of the Inclusion Center for Creative Projects, such as *Living Pictures* and *The Seagull. Fragments*. Work in the theater inspired Irina to start her own project: the SBrod Performance Lab. It features some of her deafblind and sighted and hearing partners from the Inclusion Center and has recently performed at major Moscow museums.

## Alexei Gorelov



When Alexei was invited to play a part in *In Touch*, he had been really down on his luck. He had lost his job and had to sit at home without any meaningful prospects. However, when he joined *In Touch*, he proved to be a talented and flexible performer and went on to star in other shows by the Inclusion Center: he got the part of the love-stricken Don José in *Carmen* and had several monoscenes in the *Living Pictures*. No one in the audience could believe that Alexei has virtually no sight or hearing. Now he is rehearsing a new part for another Inclusion Center production. He is also very keen on sports, such as swimming, running and triathlons. This hobby also brings in some awards; in 2019 Alexei became the first deafblind para-athlete to master the full distance of the Olympic triathlon.

**Alexander Silyanov**



Alexander is a deafblind sculptor, the director of the Usher Forum charity organization for people with deafblindness and Usher syndrome, and a member of the Creative Union of Artists of Russia. He leads an active social life, makes sculptures out of bronze and stone and takes part in exhibitions. He was presented with the Ostrovsky International Award in 2014 and the Philantropist Award, which recognizes disabled people's contributions to culture and the arts, in 2016.

**Vera Lyzhenkova**



Just like the other actors, Vera is still a member of the *In Touch* permanent cast. Her story of relationships with her loved ones always gets to people's hearts. Vera is a caring mother and grandmother who used to be an engineer. She is surrounded by a loving family, and her grandchildren make tactile holiday cards for her. Vera also plays a part in the Living Pictures choreographic performance and other projects of the Inclusion Center.

**Alyona Kapustyan**



The youngest actor in the show, Alyona chose not to rest content with her achievement. In 2019, she became the first deafblind student of the Russian State Social University college. She is now acquiring training as a social worker with the help of a tutor. In the future, she wants to become a psychologist.

# Deafblind West Australians' yarn bombing project goes global in the midst of the COVID-19 crisis!

The current COVID-19 crisis is bringing together people from all walks of life in a huge variety of creative, supportive and virtual ways. This is the story about one way we are adapting to these challenging times and continuing to reach out and bring people in the deafblind community together

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## What is yarn bombing?

The complete history of yarn bombing is lost in the mists of time and has been attributed to several different people. It is believed that the practice first originated in the United States when Texas knitters tried to find a creative way to use their leftover and unfinished knitting projects, creating a form of “inoffensive graffiti”. Yet, the start of the contemporary movement is often attributed to Magda Sayeg from Houston who coined the term after first covering the door handle of her boutique with a custom-made cozy in 2005. It attracted attention from passers-by, inspiring Sayeg to venture further with the idea of covering objects with yarn. She became curious about the idea of enhancing the ordinary, the mundane, even the ugly, and not taking away its identity or its functionality, but just giving it a well-tailored

suit out of knitting. First starting with small “yarn bombs” such as sign poles and fire hydrants in her hometown, she soon ventured into transforming urban landscapes into her own playground.

While Sayeg's foray into yarn bombing was somewhat accidental, she spurred on a global community of yarn bombers, with yarn bombing crews founded across Europe, North America and Australia. One of the first yarn bombing collectives was Knit the City from London founded by Lauren O'Farrell who has moved the concept from simple “cozies” to the “stitched story”.

The Craft Club Yarn bombers became Guinness World Record holders for the largest display of crochet sculptures, when they yarn bombed a children's hospice with 13,388 crocheted items.





Yarn Bombing Los Angeles (YBLA) is a yarn bombing collective located in Los Angeles, CA. The collective describe themselves as a group of guerrilla knitters who have been collaborating since 2010. They currently have 10+ projects in progress throughout the Los Angeles and nearby communities.

### COVID-19 hits

Unfortunately, we are now not able to meet to upskill our members and work together on this installation, and the event for the deafblind awareness week has been postponed. So our plan is to promote thought of the deafblind community and continue to make the squares. There are multiple YouTube channels that teach basic knitting and crocheting skills – these won't be accessible to all members, so in the interim we are encouraging communication guides, family and friends to support our most isolated members to start making the 20 x 20cm squares at home.

Advertising campaigns have also capitalized on the yarn bombing trend: Knit the City was commissioned by Toyota to create a 2013 installation in London.

What's yarn bombing got to do with Deafblind West Australians' Peer Support Group?

In 2019, the Deafblind West Australian peer support group, supported by Senses Australia, made a successful grant application to do a yarn bombing installation in conjunction with Deafblind Awareness Week 2020. The plan was to combine the arts, well-being and disability to improve community space with a tactile art project constructed by people with dual sensory loss, their families, carers and the extended community.

The objective of this exciting, fun and creative project was to engage members of the deafblind community in a local community tactile arts project. The overarching goal was to raise awareness of deafblindness in the broader community whilst increasing capacity, skills, creativity and inclusion. This installation will share a message of inclusion whilst beautifying the community.

A project coordinator was appointed, and work was underway planning for workshops to upskill members. A general call describing the project and its goals was also circulated to the broader community to start making squares for this installation. We received a fantastic reaction and multiple community groups are now assisting our group and donating 20 x 20cm squares that will become part of the installation.

This project and the call for knitters and crocheters to get busy was seen on social media by Roxanna Spruyt, Dbl Board member and CEO of Deafblind Services Ontario. Roxanna connected me with Karen Madho and Kelly Patterson, both from Deafblind Ontario and involved in the National Deafblind Awareness month working group. From this connection we have since met online and a lot of energy and enthusiasm has been generated about the possibility of a joint, even global project.



### Step one

Senses Australia will be hosting a National Deafblind camp in November 2020. This is our new target date for the first yarn bombing event, post the COVID-19 crisis. We are calling out globally and hope to add squares from all over the world to this exciting initiative. We will be yarn bombing a very large tree that is a part of the Heritage site at Woodman Point recreation camp. The camp is accessed by thousands of people every year, so our story and our installation will continue to be shared and enjoyed for a long time to come.



### Deafblind Awareness Week 2021

After conversations with Karen and Kelly we are now also working towards a joint event for Deafblind Awareness Week 2021. We will be hosting mutual yarn bombing events in Australia and Canada. We would love to see

this go global for Deafblind Awareness Week 2021 and have multiple deafblind communities in multiple countries hosting their own tactile yarn bombing events simultaneously!

### Get your yarn on!

So first, whilst we are all in isolation during the COVID-19 crisis, get your yarn on and start making those 20 × 20cm squares, please note they do not have to be exact, they can be bigger or smaller, no problem. Once you have a bunch, send them down to Australia to be added to the tactile art installation in Western Australia at the National Deafblind Camp, November 19–22, 2020. If you are interested in a yarn bombing project of your own as part of the celebrations of Deafblind Awareness Week 2021, please let us know.



## ■ EXCHANGE OF EXPERIENCE

There are challenging and exciting times ahead for us all. I know the deafblind community will support each other as they always do. Please feel free to contact me if you have any questions or ideas about how we can continue to move forward, connect and support our community.



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# TV caption access technology for individuals who are deafblind

Individuals who are deafblind lack access to TV information because TV accessibility features do not fit their needs. This article presents the regulation governing captions accessibility in the U.S.A., previous technologies developed to provide access to captions to individuals who are deafblind and the GoCC4All<sup>1</sup> technology that provides TV programming captions through a mobile device screen or a braille display. It also discusses the testing done with deafblind users, which resulted in an improved technology and the creation of improved captioning guidelines to always include speaker identification. These guidelines were presented to the regulator and the captioning industry. It was also proposed to the TV industry to include the GoCC4All technology in their end-user equipment in order to provide accessibility to their deafblind customers<sup>2</sup>.

## 1. Introduction

A person who is deafblind (DB) faces unique difficulties in interacting with the world around him/her. According to the National Center on Deaf-Blindness (NCDB), learning to communicate is the greatest challenge faced by children who are DB (Miles, 2008). Appropriate communication skills, education, accommodations and strategies that facilitate their access to information can prevent DB individuals from being isolated and allow them to make their thoughts known and express their needs and desires. Individuals with DB must have the same level of access to information and facilities

as those individuals who do not have sensory challenges.

The impact of the information that is disseminated through television on the development of our society has been thoroughly documented during the past 25 years. This fact is supported by evidence-based research in the fields of education, politics, economy, sociology and psychology, among others (Slavin, 2002, p. 15-21; Denzin & Lincoln, 2011; Meier & O'Toole, 2008, p. 4-22). In addition to bringing information to the audience, TV gives entertainment; encourages dialogue and socialization among families and friends by sharing information about series, movies or

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<sup>1</sup> The project GoCC4All: Using Pervasive Technology to Provide Access to TV to the Deafblind Community is funded by the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR grant number 90IFDV0004-01-00).

<sup>2</sup> The contents of this article were developed under a grant from the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR grant number 90IFDV0004-01-00). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this article do not necessarily represent the policy of NIDILRR, ACL or HHS, and you should not assume endorsement by the Federal Government.

shows; and can be utilized as an educational tool, especially for children.

Until now, access to TV for the DB community has not been considered in the U.S. The media industry, the regulatory agencies or the access to media industry serving other populations with sensory disabilities have not addressed the need for access for the DB community. Considering that one of the most significant means to access information is mainstream technology intertwined with assistive technology, this article focuses on captioning for TV information access as an example of this combination of AT and mainstream technology. The current regulation in the U.S.A. governing accessibility and captioning in particular is presented as background.

### 1.1. Government recognition of the importance of equal access to TV or people with sensory disabilities in the U.S.

The existence of legislation regarding CC and video description shows that the government recognizes the importance of providing equal access to information to individuals with sensory disabilities. In the United States, the Americans with Disabilities Act (ADA) of 1990 was an important regulatory milestone. It prohibits discrimination against persons with disabilities in employment, state and local government services, businesses that are public accommodations or commercial facilities, and transportation. Title III of the ADA requires that public facilities, such as hospitals, bars, shopping centers and museums, provide access to verbal information on televisions, films or slide shows ("Nondiscrimination on the Basis of Disability in Public Accommodations and Commercial Facilities," 2010).

ADA was later complemented by the Telecommunications Act of 1996. It required the Federal Communications Commission (FCC) to ensure that televised video programming was fully accessible through the provision of closed captions. In 1997, the Commission adopted rules that required captioning on all-new English and Spanish

The existence of the technology is not enough to provide access, as it will be shown in the following paragraphs. It will be presented how a commitment from the accessibility industry and the regulators could make access possible.

This article includes a summary of the technologies developed to bring captioning to the DB, including the most recent one, GoCC4All, developed by Dicapta Foundation and funded by the DHHS, as well as the results of the testing of GoCC4All done with the DB community. It shares the actions prompted by the testing and also the proposals, led by Dicapta Foundation and its advisory committee, to the FCC, the captioning industry, and the TV industry that look for improving TV access for the DB community.

language programming. Later the Twenty-First Century Communications and Video Accessibility Act of 2010 required the closed captioning of online video content that was originally broadcast on TV with captions.

Offering high-quality CC is key to serve the needs of people with hearing disabilities. On July 23, 2004, advocacy groups representing individuals who are deaf and hard of hearing filed a joint petition for rulemaking seeking amendments to the FCC's captioning rules on matters of captioning quality, scope and enforcement. This petition and subsequent work brought about the publication of the FCC's 2014 Closed Captioning Quality Order that defines four non-technical quality standards (best practices) as the components necessary to ensure that CC fully and effectively conveys the content of television programming: accuracy, synchronicity, completeness and placement ("Closed Captioning Quality Report and Order, Declaratory Ruling, FNPRM," 2018, p. 20).

Despite those efforts for quality, the DB community is still not served; their communication barriers to access captions or description have not been addressed.



## 1.2. Technological developments related to TV access to serve people with sensory disabilities

To access TV, individuals who are DB need assistive technology that accommodates not only to their hearing loss, like CC, but to their visual challenges.

Several technical developments have adapted existing assistive technology that is used by blind or deaf individuals, by turning aural and/or visual outputs into tactile outputs. Those technical developments increase communication opportunities for the DB community (Hersh & Johnson, 2008, p. 193-215).

Documented experiences using braille displays to deliver television captions to people who are DB include the following two prototypes: The Braille TeleCaption System, with output available in braille and large print, funded by a federal grant in 1989 (Biederman-Anderson, L., 1989), and the Closed Caption/Braille Computer System (CBCS) in which a videotape recorder sent captions to a braille computer card into an IBM compatible computer ("Braille Telecaption System," 2007). The concept elicited positive results among the users. However, the high costs of technology, as well as limited commercialization possibilities due to the low incidence of deafblindness, prevented further developments based on those prototypes.

Outside the U.S., the development of CUPID, an information management system, won in 1996 a SMART award from the U.K. Department of Trade and Industry. Cupid could run on a wide range of computers and used three forms of serial output: speech, tactile output, and a word-at-a-time visual display which had large characters for reading by partially sighted people ("Equipment for Deafblind People Page," n.d.). To date, none of these prototypes or systems are in operation.

Apart from TV captioning, there have been initiatives to provide other types of captions to individuals who are DB. In 2013,

NPR Labs, the Public Radio Satellite System (PRSS) and Maryland's Towson University produced live-captioned radio programming and braille radio programming (Tayler, 2013). The radio broadcast dialogues were converted into text and sent to a caption editor who corrected and formatted the information for readability. The captioning feed was then modified for use with standalone refreshable braille displays.

Ultratec, a company that offers phone captioning services, uses its CapTel 880iB phone technology to provide braille captions of phone conversations ("Braille CapTel Service," n.d.). The phone can be connected to a braille display where the user can read word-for-word captions of what a caller is saying.

In recent years, Apple has taken into consideration communication with braille displays in its accessibility features. VoiceOver users can access closed captions and subtitle tracks audibly or through the braille displays on their iPhone or iPads ("Iphone - As accessible as it is personal," 2018). In addition, Apple TV lets VoiceOver users access closed caption and subtitle tracks through their braille displays ("Hearing Accessibility TV," n.d.).

During 2019, Dicapta Foundation<sup>1</sup> launched GoCC4All, a technology aimed at delivering TV captions to individuals who are DB and who otherwise have limited or no access to captions.

The development took into account two aspects: the provision of a customizable technology to respond to the diverse needs of the DB community, such as different levels of vision and/or hearing loss, and the use of low-cost technology to assure its sustainability. The following section explains more details about GoCC4All development and the technology itself. It also talks about the testing done with DB users.

<sup>1</sup> Dicapta Foundation is a non-profit organization whose mission is to ensure equal access to information for people with hearing and/or visual disabilities.

## 2. GoCC4All

### 2.1. Development and Concept

For the design and development of GoCC4All, Dicapta Foundation teamed up with the research group SoftLab from the University Carlos III of Madrid (UC3M). The UC3M, Telefónica and the Federation of Deafblind People (FASOCIDE) launched in Spain the PervasiveSUB technology; a pioneer technology in the world that allows people who are DB to receive and enjoy the contents of television at the same time as the people around them (García-Crespo et al., 2018). Although European and American TV systems requested a new system to be created, the new development benefited from similarities in the population to be served.

To make sure GoCC4All provided the best experience possible to the users, we have taken into account universal design principles, such as multiple means of representation, action and expression and engagement (CAST, 2011). Customization options are essential since “the population of people who are DB is quite diverse. Each person who is DB has a unique life experience based on several factors including their sensory abilities (how much they see and hear), the age of onset (when they became deaf, blind and DB), educational and cultural background and whether or not they have additional disabilities” (“Introduction to Deaf-Blindness,” n.d.).

GoCC4All also uses pervasive computing which combines current network

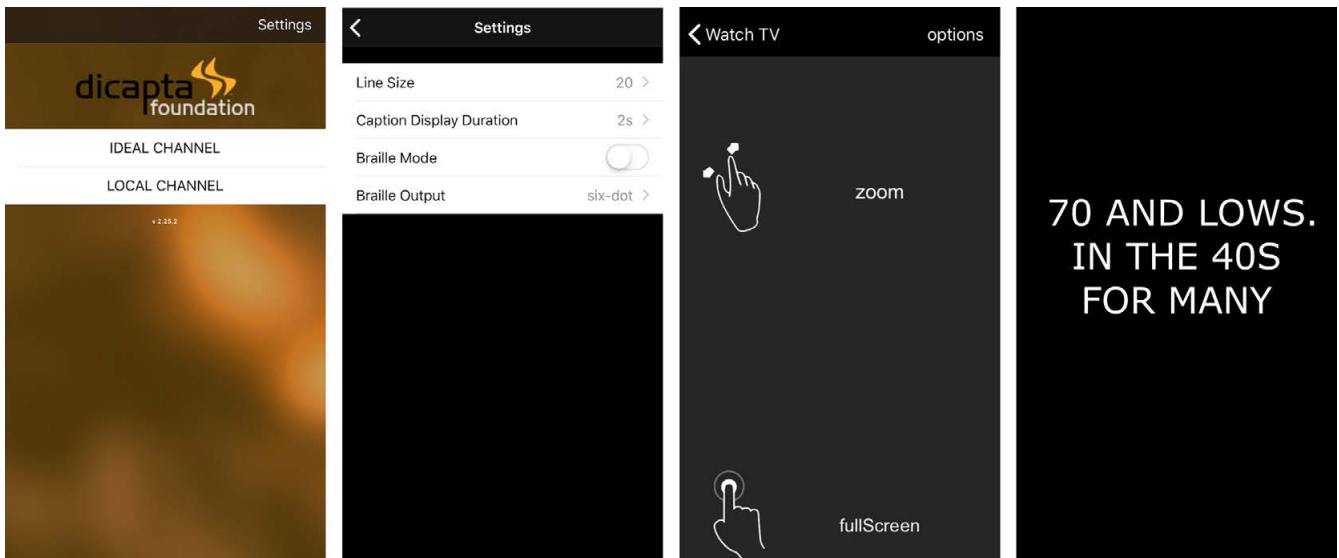
technologies with wireless computing, voice recognition, Internet capability, and artificial intelligence. The goal of pervasive computing is to create an environment where the connectivity of devices is embedded in such a way that the connectivity is unobtrusive and always available (Cámara, J., Bellman, K. L., Kephart, J. O., Autili, M., Bencomo, N., Diaconescu, A., ... & Tivoli, M., 2017).

Within this framework, GoCC4All receives broadcast captions from TV programs and shows them through a mobile device and a braille display; giving those who are DB the possibility to customize the reception of captions according to their particular needs. The mobile device user can easily customize the size of the characters. The braille display user can customize the speed of captions delivery. GoCC4All is compatible with different braille displays.

The GoCC4All technology, as shown in Figure 1, has two components: hardware that attaches to the TV cable receiver; and an app that is compatible with iOS and Android operational systems. The hardware communicates via Wi-Fi with the mobile device to send live captions. Those captions can be seen in the mobile device or can be sent to a braille display via Bluetooth. A few screenshots of the app are included in Figure 2.



**Figure 1.** GoCC4All components



**Figure 2.** GoCC4All screenshot samples

## 2.2. Collecting feedback from GoCC4All users: an iterative development

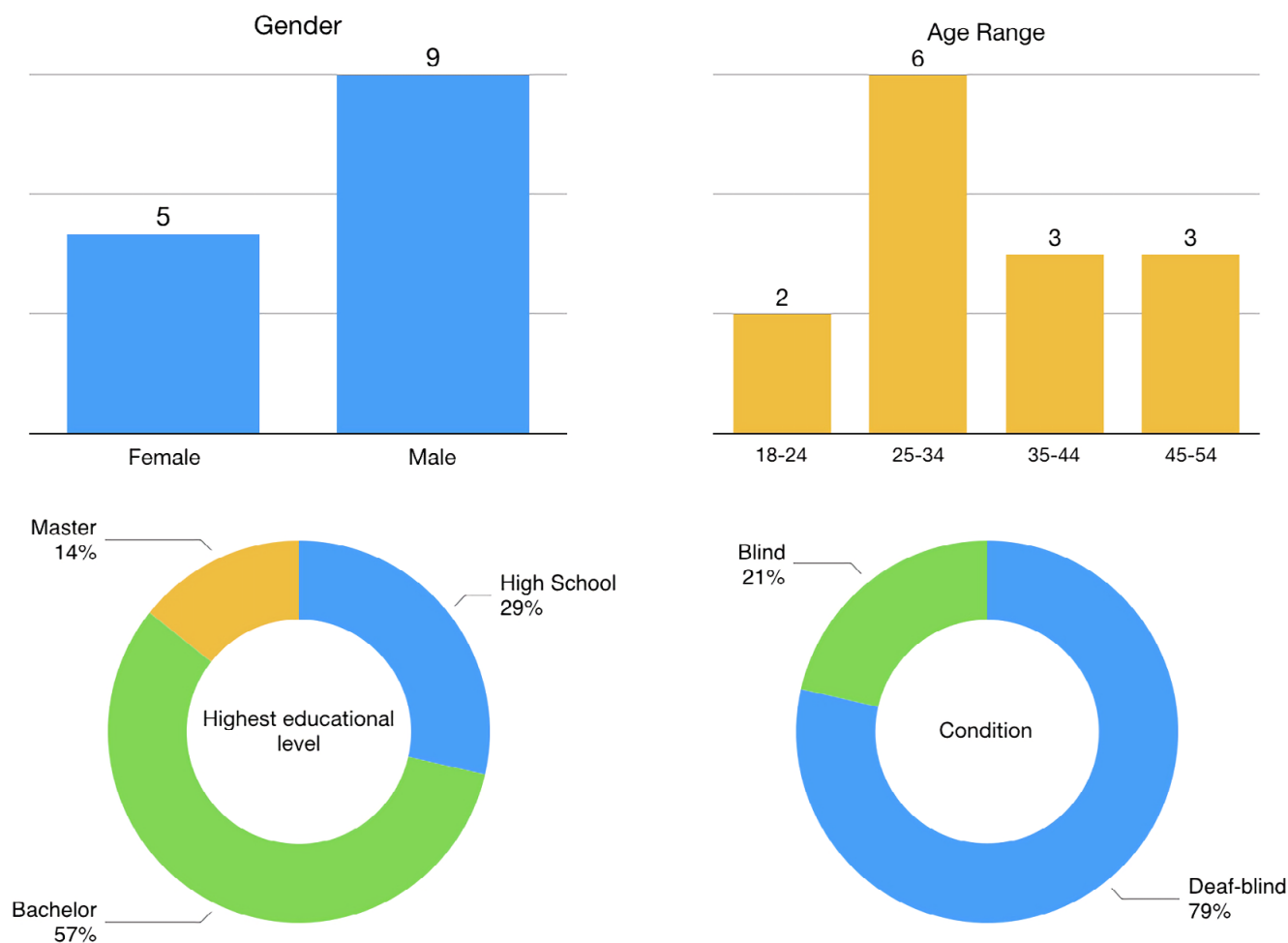
In addition to using universal design principles, Dicapta Foundation worked under the guidance of an experienced Advisory Committee formed by people with disabilities, representatives from organizations serving the DB community, technical experts and key personnel from Dicapta Foundation. The Advisory Committee has representatives from the Helen Keller National Center, National Center on Deaf-Blindness, Perkins School for the Blind, Florida and Virgin Islands (FAVI) Deaf-Blind Collaborative, Lighthouse Central Florida and DeafBlind Citizens in Action.

The Helen Keller National Center (HKNC) supported the testing of GoCC4All by identifying DB individuals to participated in the technical, accessibility and usability testing. It also trained and communicated with the test participants, helped to evaluate the benefits of using GoCC4All and will participate in the design of the transfer plan of the technology to the community.

This project's research protocols were revised and approved by a private research

review board before contacting survey participants. A qualitative model, using a questionnaire, designed and validated by the researchers, served as the tool to collect the opinions of the participants. Participation was voluntary and each participant received information on the purpose of the project's research/development and signed a consent form prior to participation. The questionnaire was sent through email and was analyzed using categorizations as deemed necessary to answer the research questions.

Tests participants were selected based on the following criteria: a) have a diagnosis of deafblindness, b) were users of a smartphone, and c) were braille users. Due to the difficulty in finding DB participants, a few blind individuals who were users of smartphones and braille displays were included in the surveys. Nine adults participated in the iterative technical and accessibility testing, and 14 adults participated in the usability testing. Figure 3 shows the demographics of the participants in the usability testing.



**Figure 3.** Demographic data of usability testing participants

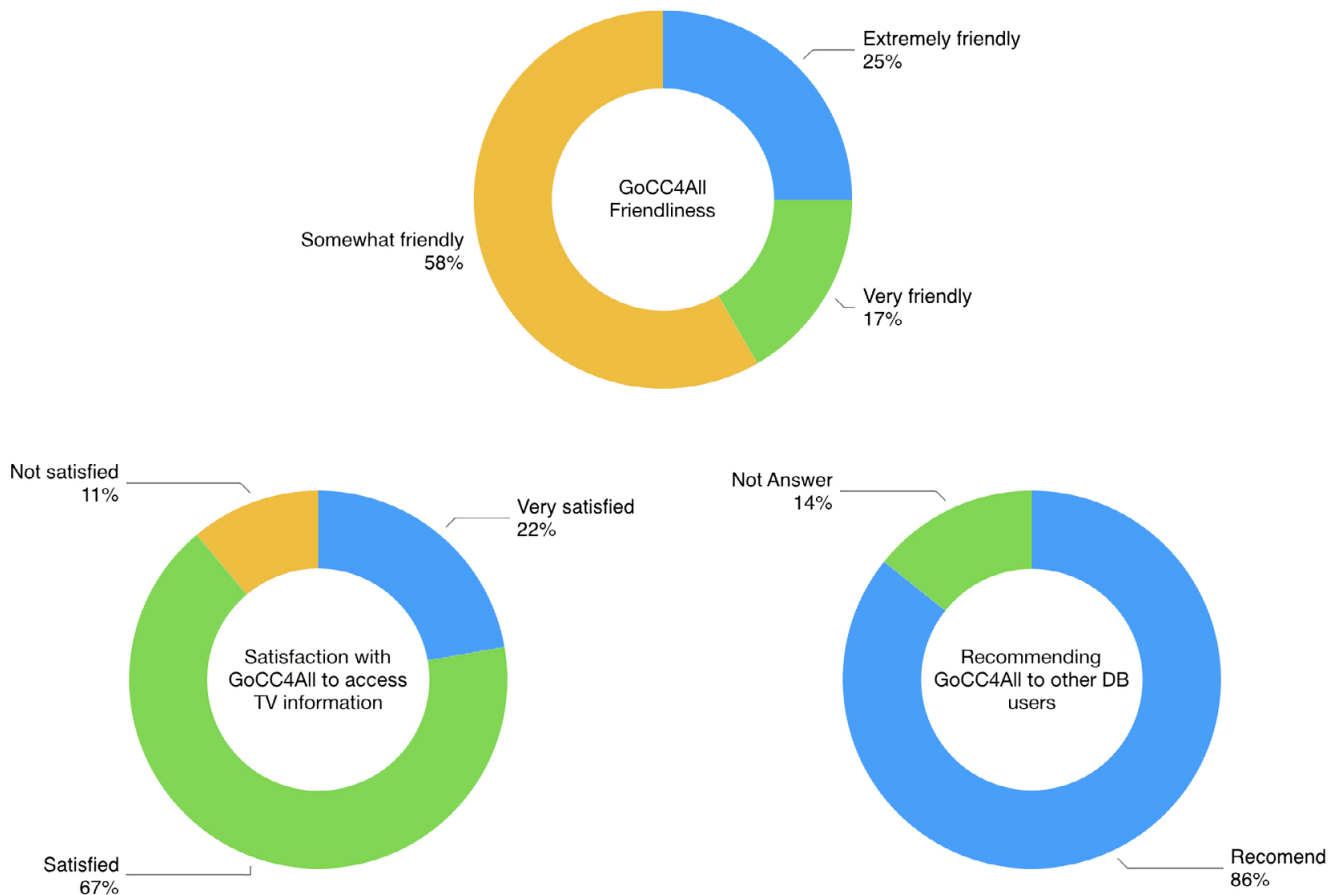
The technical testing was done in two stages. The first stage had the participation of two experts on accessible technology that evaluated the app from a functional perspective. The second stage included seven technical testers that are advanced users of accessible technology. They were asked about their testing setup (braille display, operational system and the TV service provider used), the easiness and accessibility of the process to set up the system (software and hardware) and the provided documentation. The recommendations resulting from the testing were used to fine-tune the app and the companion documentation.

An additional result of the technical testing was the realization of the need of always including speaker identification in captions. Because of that, we created an “ideal channel” that offers captions for 12 hours of programming with the differentiating

characteristic that these captions always include speaker identification. That channel was added to the broadcast channels available for usability testing. Through a channel menu, the users had the option of receiving the captions from a channel they selected through their cable box, the PBS channel captions or the Ideal Channel captions. The PBS and Ideal channel were provided directly to the app without the need of a cable box.

The 14 participants in the usability testing (11 DB and three blind) were surveyed about their access to information from TV before using GoCC4All, their satisfaction with GoCC4All to access TV information, their recommendations for improvements and their suggestions about strategies to use to transfer GoCC4All to the DB community. Below we summarize the results of the usability testing. Figure 4 also shows some of the results of this testing.





**Figure 4.** GoCC4All friendliness, user satisfaction, and recommending to others

**Question #1.** How did you access information from the TV prior to the use of GoCC4All?

Most of the participants (nine of 14) expressed that they were unable to access information from TV prior to using GoCC4All. They expressed that they accessed information from TV through family and friends (seven participants). In fact, only one of the 14 participants used GoCC4All to watch TV for entertainment. When utilizing GoCC4All, 11 participants watched the Ideal Channel designed by Dicapta Foundation; whereas three participants accessed TV using the HKNC cable TV. Of the 14 participants, only five have cable service at home.

**Question #2.** How satisfied are you with GoCC4All to access TV information?

Most of the participants were satisfied with GoCC4All to access TV information (8 of 14), one (1) was not satisfied and the other participants didn't answer. Two more questions were related to user satisfaction with

GoCC4All. Seven of the participants considered GoCC4All somewhat friendly, while the rest considered it either extremely friendly or very friendly. Twelve of the participants said they would recommend the GoCC4All for other DB people. Figure 2 summarizes these findings.

**Question #3.** Recommendations regarding GoCC4All software and hardware.

One participant recommended a beep for storm updates or other emergencies. The rest of the participants didn't make any recommendations.

**Question #4.** What kind of strategies should be used to transfer the GoCC4All app to the DB community?

In a campaign to promote the use of GoCC4All, the participants recommended using flyers, social media, professional development conferences and national organizations such as the Hellen Keller National

Center, National Center on Deaf-blindness, the National Association of the Deaf and the Association Foundation for the Blind. They also recommended promotion through email lists, radio and schools for the DB.

After solving the technological barrier with GoCC4All, the lack of identification of the

speaker in TV CC was identified as the main barrier for this technology to serve the audience. For that reason, an immediate call to action was made to the FCC and the captioning industry. And additional call to action was made to the TV industry. They are presented in the following section.

### 3. Call for Action looking for captions accessibility for the DB community

Three actions were identified as facilitators for GoCC4All or similar technologies to be incorporated to support access to TV for individuals with deafblindness.

Following a brief description of each of those is shared with the purpose of raising attention in the field.

#### 3.1. Speaker identification in captioning

##### 3.1.1. Suggesting modifying regulation

As mentioned in section 1.1, the FCC's 2014 Closed Captioning Quality Order defines four non-technical quality standards: accuracy, synchronicity, completeness, and placement. Paragraph 29 mentions that "in order to be accurate, captions must also provide non-verbal information that is not observable, such as who is speaking" ("Closed Captioning Quality Report and Order, Declaratory Ruling, FNPRM," 2018, p. 22). It also states that "if there is more than one speaker, the proper placement of captions dictates that each speaker be identified, through caption identification or caption placement, so that viewers can understand who is speaking at any given time. When a speaker is not on the screen, identification of that individual in the caption text must also be provided if viewers not using captions are able, from the program's audio content, to discern

the speaker's identity" ("Closed Captioning Quality Report and Order, Declaratory Ruling, FNPRM," 2018, p. 23).

However, placement itself is not enough for the identification of the speaker by those who are DB. Even though GoCC4All users can read captions on the screen of their mobile devices or braille displays, the captions have little or no meaning for them because without the identification of the speaker.

Because of that, on November 26, 2019, Dicapta Foundation together with the project's Advisory Committee sent the FCC a petition for the expansion of the speaker identification requirement included in the non-technical quality standard of accuracy. This petition included suggested guidelines for speaker identification.

##### 3.1.2. Inviting the captioning industry to modify their guidelines for speaker identification

In the same line of thought, Dicapta Foundation together with the members of its Advisory Committee shared with several companies in the captioning industry the suggested guidelines for speaker identification. In the belief that having industry consensus allows for the strongest impact to make captioning accessible to individuals

who are DB, the industry was asked to consider those guidelines and adapt them to their needs. Any consistent code or convention to identify the speaker, based on letters and symbols available in braille displays ("How to Use the Braille Alphabet," n.d.), will allow people who are DB to have full access to information on television.

### 3.1.3. Suggested guidelines for speaker identification in captioning

1. When the speaker's name is known, the speaker's name should be included. When possible, use the entire name of the character. If that is not possible, use the character's initials.

**Examples:**

(Robert Smith)<sup>1</sup>

Let's do it!

Robert Smith: Let's do it!

(R. S.): Let's do it!

R. S.: Let's do it!

2. When the speaker's name is unknown, identify the speaker using the same information a hearing viewer has.

**Examples:<sup>2</sup>**

(female #1)

I'm happy.

(male narrator)

That is wonderful!

3. When more than one speaker has the same name, use numbers to identify them in order of appearance. The last name could be used as well.

**Examples:**

(Robert #1)

Let's do it!

(Robert #2)

Yes, let's not waste time.

Or,

(Robert Smith)

Let's do it!

(Robert Wilson)

Yes, let's not waste time.

### 3.2. Proposal to the industry about integrating the GoCC4all technology in their equipment

The physical connection of the GoCC4All hardware to the TV cable box makes possible to show to the users the captions of the channel they select. However, connecting additional equipment to the TV can be cumbersome for anybody and more so for people who are deafblind.

We proposed that companies in the TV industry integrate the GoCC4All technology in their end user's hardware to make TV access possible for the DB community. Dicapta Foundation offers to transfer the GoCC4All technology to other companies so that the overarching objective of providing access to the DB community becomes a reality.

<sup>1</sup> This example follows the guidelines suggested by the Described and Captioned Media Program. "Captioning Key. Speaker Identification." [https://www.captioningkey.org/speaker\\_identification.html](https://www.captioningkey.org/speaker_identification.html)

<sup>2</sup> Ibid.

### 4. Conclusions

In conclusion, there is a need of a group of people with sensory challenges that requires assistance in accessing information that is available to the general population. CC in television is a foremost technology for accessing information for people with hearing loss, however CC by itself is not enough to provide access to individuals who are DB.

GoCC4All is a technology that responds to the diverse needs of the DB community by providing customizable options for the reception of captions.

The feedback of DB testers provided critical information to improve GoCC4All and drove the generation of an ideal channel that always includes speaker identification in its captions. This ideal channel can serve as a gentler introduction to TV thanks to the identification of the speaker and the fact that the programming runs again every 12 hours so viewers can revisit the programming. This channel can be accessed through the GoCC4All app without needing a cable provider.

Feedback from the users also prompted a look into the current captioning regulation

and the creation of suggested improved captioning guidelines for speaker identification. These guidelines have been presented to the regulators and the captioning industry to call their attention to TV accessibility for DB and encourage action toward the provision of accessibility for this community. The TV industry has also been contacted to point out the needs of the DB community and to ask it to make its end-user equipment more capable to connect to devices that provide accessibility to the DB population, such as of GoCC4All, or provide the accessibility themselves. Regulators and the industry play a pivotal role in access. The existence of the technology alone is not enough to provide access. There has to be a commitment from those two players to make access possible.

Lastly, the DB community is willing to be part of the process of the design and implementation of new devices that are meant to serve them. "Nothing about us without us" (Charlton, 1998); this mantra should lead the creation and development of new technology to serve people with disabilities. It means that any project gear to serve a group, should not be developed without the direct participation of those that will be affected.

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# Robin device for blind individuals

SENSOR-TECH  
LABORATORY

Globally the number of visually impaired people is estimated to be 285 million, of whom 39 million are blind. Further, the number of blind people is set to triple by 2050, rising to 115 million.

For every blind or partially sighted individual you see getting on with their lives, there are many more who are trapped inside their own home, afraid to leave the house and reliant on friends, family and assistants to carry out the most basic of day-to-day tasks. Modern society is condemning people with sight loss to a life of loneliness, dependence and vulnerability.

It does not have to be this way. There is no reason why blind individuals cannot live full and independent lives, build successful careers, travel the world and start a family. Experts of the Sensor-Tech Laboratory have found a solution:

the smart assistant Robin. It is a smart gadget that helps visually impaired and deafblind people to navigate the world and lead a more comfortable and independent life.

Robin is a small wearable device. In its shape, it resembles a camera that fits comfortably into the user's hand. One can control the functions by pressing buttons. The device does not require an internet connection or any third-party applications to operate. Setting up the device has never been simpler: just turn it on and start using.



The smart assistant Robin has several important features. It can detect objects and people around and calculate the distance to them. The device works in the following way: first, the user has to point the device at the object; the device then scans the object and notifies the user via headphones what kind of object or person is nearby.

The recognition radius of the device is 10 meters. This allows the user to identify both obstacles and objects in advance. Thanks to the facial recognition feature Robin can recognize your loved ones in a crowd of people. The user must upload the photographs of friends and loved ones and can then start the conversation first.

To warn the user about an unexpected obstacle, Robin transmits the information through a series of vibrations of different intensity. The vibrations intensify as the person or object moves closer so the user has enough time to stop.

Elena Kakorina who has sight and hearing loss shared her positive experience of using the smart assistant Robin:

“This device would be a faithful helper to me. I would get to the bus station by myself, the attendant would accompany me in the subway, and I would visit people more often. Now it is hard for me to visit my grandchildren and my relatives help me. But with this cane I would be more independent”.

Ten-year-old Miroslava Popova also noted that Robin helps her to feel more independent. She was born with multiple visual impairments and congenital malformations. Miroslava took part in the trial of the gadget and it is now her dream to own one. To make her dream come true, a charity football match was held. Caring players and fans managed to raise the necessary amount to purchase the device.

In addition to this device, experts of the Sensor-Tech Laboratory have developed other important and useful gadgets for people with sight and hearing loss. The main goal of our laboratory is to help deafblind people and people with sight and hearing loss to feel safe and comfortable in the society and the world around them.



# If you can see it, you can support it

## CAROLINE LINDSTROEM

SPECIAL  
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When we put on our language glasses and give bodily tactile utterances a linguistic value, we can communicate linguistically with people with congenital deafblindness.

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Photo:

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The Nordic network on tactile language, coordinated by the Nordic Welfare Centre, has published a book about tactile language to benefit people with deafblindness and their families as well as professionals in this sphere. Many people with congenital deafblindness face the risk of being misunderstood as their communicative expressions, for an untrained eye, can be difficult to read. The motto of the book is therefore: If you can see it, you can support it.

Knowledge about language development in relation to congenital deafblindness is continually changing and developing, and therefore a shared focus functions as an important precondition for insights and new perspectives. The Nordic countries have been collaborating for several years, focusing on the topic of tactile language since 2009. Participants from Norway, Denmark, Sweden and Iceland have been working together to spread knowledge about tactile language through seminars and courses, and as a result of that the network was formally established in 2014.

The starting point for the network is that humans are languaging right from birth and that all people want to tell about and share their feelings, thoughts and experiences with others. When we accept a bodily engagement in the world as the basis for understanding

and realization, it makes sense to look for language that emerges from the body's experiences of being in the world.

The book offers suggestions on how close relatives of people with congenital deafblindness and people with dual sensory impairments can spot and read utterances in the bodily tactile modality as language to overcome the challenges of low readability and isolation. It also suggests how to respond to these utterances and how to support further development by using different cognitive strategies in the dialogue.

The book consists of 19 separate chapters, each addressing one or more aspects of tactile language, and together they illustrate the complexity as well as the wider perspective in the understanding of language development through the tactile modality. One of the chapters is a story written by Grete A. Steigen, mother to Tormod, a young man with congenital deafblindness. Grete tells a story about their mutual journey through life and how putting on their language glasses helped them to learn what to look for and put words to Tormod's bodily tactile language.

Grete's article is presented in the following text as an extract from the book: "If you can see it, you can support it."

### **How Tormod and his family created a common language – and achieved new competences**

Grete A. Steigen

This is the story about Tormod and his family. About how they got to be professionals around their own child. About how they learnt to look for and put words to Tormod's bodily tactile language.

"It was not possible to get my head around at day 1 or day 101 or 1001 or 100001 what the world looked like for Tormod. Even today it is hard to understand. But today we know a lot more. It was good for Tormod and the rest of us have been able to share this journey."

"It was exactly as the professional who came from State Central Team for the Deafblind said: It will be a good investment for you to learn proper sign language. And I knew he was right. In hectic everyday life, none of us got around to do that. In addition to

everything else. It is what I regret most that I never got around to do, being Tormod's mother," Grete Steigen says.

Today Tormod is a young man with congenital deafblindness as part of a CHARGE syndrome diagnosis.



Tormod entered the family Steigen/Johnsgaard in August 1986. Just about 14 months younger than the big brother, Jonas. Olai, the younger brother, was born in 1989. The parents, Jan Ole and Grete, were young parents, just 25 and 22 years

old. They were new as farmers as well. They had professional ambitions. They wanted to expand their farm and wanted to make a living from dairy farming, way up in the mountains, in Soemadalen, next to Sweden.

### Story of the family

“Jan Ole reminded me, we were quite controversial in the mid-eighties. Because we used every opportunity to tell Tormod’s story. And we brought Tormod with us.

Everywhere. He was a visible child. And he caught every eye being so different. With his minor and major lack of functions,” Grete says.

Tormod had a diagnosis no one had ever heard of. CHARGE in Tormod's world was oesophagus atresia, no passage for air through the nostrils, pupils shaped as key holes and severe hearing loss. In addition, Tormod was tiny and did not put on weight. But the will to live got a top score.

"The grandparents came to visit Tormod early October," says Grete. A touching picture of Grandad meeting his skinny grandchild Tormod for the very first time. Tormod with plastic tubes sticking out from his nose. We, the parents, thought Tormod had made huge progress over the first six weeks. The grandparents saw a tiny, fragile grandchild."

### The society around

"I remember I waited for 'someone'. 'Someone' who could guide us in the jungle of sick pay and future. Eventually we got a more or less secure grip," Grete says.

And quite soon the family got in touch with Frambu, a center for rare disorders. A cousin worked at the Skådalen School for deaf children in Oslo. So via Frambu and the cousin they got in touch with the support service for the congenitally deaf-blind.

### Meetings in unknown territory

Tormod and his family got to be a part of the movie "Møter i ukjent landskap" (Meetings in unknown territory), created by Knut Klæboe. The movie told the story of people with congenital deafblindness of all ages. Tormod was the youngest.

"He was out walking in mountain scenery with his great grandmother." A great

### Early support

The family was supported by a service that saw the importance of good networks. And the family network intertwined with the professional Skådalen school for the congenitally deafblind. It was possible for them to be part time at the school and they got

The extended family was to be the closest help and network for Grete and Jan Ole. All generations. They have recruited lots of good helpers over the years. Tormod and uncle Reidar Martin are long time pals. 15 years and counting. Reidar Martin started out as Tormod's teacher and followed Tormod home to his grown-up life. In Tormod's grown up life in his own residence. Reidar Martin manages Tormod's house and staff. Often, you can find them out in the wilderness, skiing, kayaking or just rambling the 5 km down to Tormod's own little cabin, Bua-mi.

Tormod had an early assessment at the specialist department of Skådalen School. Pen was hardly put to paper on The model on interaction, the well-known work of Anne Nafstad and Inger Roedbroe.

"We were lucky. We came into the field of deafblindness just at the dawn of a new era. This shift made us think 'sky is the limit'. Tormod was only 4–5 years of age when we decided that our small rural town should be his future. This was a controversial choice, not supported by professionals."

grandmother with the same extraordinary spark of life as Tormod, Grete says. "Being a part of this movie made us believe we were well able to create a great life for Tormod here, amongst us. A life worth living, based on local values. Based on a close community. An everyday life linked to the farm work and the nature surrounding us."

the support and inspiration they needed to maintain everyday life at home.

"The overall task was to communicate with Tormod. And to learn to interpret his own voice. A bodily tactile language with low readability."

However, Tormod became a specialist in spatial communication. He took Grete and his family to places where he had been experiencing something worth telling.

Grete continues: "It took time for us to understand he had something to tell us. This field of knowledge and we have been learning in sync. We came into this field in times of change. Experiences from Norway, Scandinavia and Europe came to the family through close cooperation with groups of highly competent professionals giving us easy access to competence and the latest knowledge. And we contributed to the development of this knowledge as well. Without

### Negotiated signs

"At one point we decided the natural thing for Tormod was to build a cabin. As a part of a language project," Grete remember.

Guided by senior supervisor Kari Schjoell Brede at Eikholt, the manager at Tormod's house Reidar Martin Steigen and Skådalen School for deafblind children, they started a project. Tormod and a pupil at Skådalen were apprentice carpenters. The idea was to monitor closely what development they could find by working with meaningful activities. The start point was well known, a little house, they then expanded out from the well-known negotiating every sign. They negotiated every sign for both the participants. It took a while and time was an important factor.

"This influenced us all, Grete says. By going back and repeating – how did we build these walls?" First a wooden framework, then the timber roof trusses, then all the screws. It was not just physical scaffolding for a cabin, but also a mental scaffolding. This scaffolding enlightened the process for us all.

### Learning from video analysis

The teachers and the pupil from Skådalen shared their knowledge with Tormod's staff and network. Kari and several interpreters shared their competence in sign language and communication. A lot of the events were filmed and immediately analyzed. Some of

this access to knowledge, it would not have been possible to develop a high quality of life in rural Norway. And these highly qualified people wanted to cooperate with us. I think we made contributions as well," states Grete.

In the early eighties parents and professionals were seated at different tables. The parents could come and share their experiences with the people of knowledge, for example at Nordisk Uddannelsescenter (NUD) (Nordic Education Centre) for professionals, but we were not let into the discussions with them. But this changed with the meetings in the communication groups formed around each child with CDB.

To build a cabin is real world – authentic. There is a long line of issues that need to be solved. They had a solid professional carpenter working. He was skilled, to him it was not a problem to guide a deafblind person through building a house.

There were good expectations to the story as well. Waiting for critical moment when the timber is to be cut by the saw, with one part falling to the ground. These were the moments of great expectation for both apprentices.

"Waiting for just that moment, the moment of the fall. This made tactile traces!" Grete says. "For Tormod this particular trace was set on his forehead. He felt the work of the saw in the timber with his forehead. And that is where we find this particular sign for this particular event; on his forehead. When we look for signs, we often look in the wrong places. We see past the experience and look for the words."

the films have been analyzed repeatedly by several professionals. To find new knowledge about the complex bodily tactile communication. Through these analyses they learnt a lot about what Tormod's own language looked like.



Video analysis has always been in use in this field and still is. It has been an important tool to unveil Tormod's language competence. The knowledge about bodily tactile expressions is just recently described.

"Maybe we can say the understanding of bodily tactile language has been in sync with Tormod," Grete reflects.

We hope you enjoyed selected parts of the first chapter of the book, which also contains case descriptions, theoretical perspectives and hands-on ideas. We hope you are inspired to order or download the book and read the other 18 chapters, too. The book can be downloaded from the Nordic Welfare Centre:

<https://nordicwelfare.org/publikationer/if-you-can-see-it-you-can-support-it-a-book-on-tactile-language/>

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# 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](mailto:r.spruytrocks@deafblindontario.com).