

Dbi REVIEW

THE MAGAZINE
OF DEAFBLIND
INTERNATIONAL



LARGE CORPORATE MEMBERS

THE NATIONAL RESOURCE CENTER FOR DEAFBLINDNESS

THE GERMAN DEAFBLIND CONSORTIUM

ABLE AUSTRALIA

SENSESWA

SENSITY

LEGA DEL FILO D'ORO ONLUS FOUNDATION

DEAFBLIND ONTARIO SERVICES (CANADA)

ONCE AND ITS DBI COMMITMENT

ROYAL KENTALIS

SENSE

PHOTO: SENSE



Show that you are a part of Dbl!

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



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

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

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ADDRESS BY THE VICE PRESIDENT OF DBI

➔ 3

NEWS

Save the Date! The 18th Deafblind International World Conference

➔ 4

Supporting Tactile Cognitive Potentials: the TWMS Supervisor Training Course

➔ 5

Inclusive Education for Learners with Multisensory Impairment: Best Practices and Research Priorities

➔ 7

Baptism and Launch of the Deafblindness Collection: Practical Guide to Usher Syndrome

➔ 8

News from the Anne Sullivan Foundation, Ireland

➔ 12

Intervener/or Community of Practice

➔ 13

NEWS FROM NETWORKS

The Ibero Latin America Network report

➔ 15

Deafblind Education Network

➔ 16

Technology Network

➔ 17

Communication Network

➔ 19

Family Network

➔ 21

LARGE CORPORATE MEMBERS

Able Australia

➔ 23

SensesWA

➔ 24

The National Resource Center for Deafblindness

➔ 25

Lega del Filo d'Oro Onlus Foundation

➔ 27

The German Deafblind Consortium

➔ 29

Sense

➔ 30

Royal Kentalis

➔ 32

Deafblind Ontario Services (Canada)

➔ 33

■ CONTENTS

ONCE and its Dbl Commitment

→ 35

Sensity

→ 36

ARTICLES

An Analysis of Factors That Promote Transition of Learners with Deafblindness to Independent Living

→ 38

Ecological Assessment and Individuals who are Deafblind

→ 43

The Importance of “Yes” and “No” for Students with Visual Impairment and Additional Disabilities

→ 46

Meeting Problem of Lack of Independence in Communication and Services Accessibility with HaptiBraille

→ 50

INTERVIEW

Saskia Damen, “Joining Forces towards the Most Effective and Sustainable Treatment Methods”

→ 54

NETWORKS AND NETWORK LEADERS

→ 57



Connecting and Collaborating Around the World: That is Dbl!

It has been 3.5 years since Dbl set out to truly become THE point of connection in deafblindness worldwide.

We have made quite some progress on this way which, among else, includes the following:

- The reorganization of our outreaching communication as a teamwork of the Communication Committee ComCom and numerous Communication Ambassadors throughout the world;
- The research initiative and the conference in Africa;
- The ongoing great project for an ICF core set for deafblindness;
- Joining forces with the International Communication Rights Alliance;

- New or strengthened collaborations with the WFDB, ICEVI, WFD, and IDDC;
- The upcoming global campaign together with some of these organizations that calls for the immediate respect of the right to education for all children who are deafblind and have similar needs;
- Growing, financially better supported and wonderfully active Dbl Networks;
- Increasing number of members.

The members indeed are the key. It is, their experience and competence, their passion and their commitment, that makes Deafblind International a wonderful global network organization.

All, indeed ALL members of Dbl are VIP members. However, Dbl would not be possible without

MIRKO BAUR

VICE PRESIDENT
OF DBI

ADDRESS BY THE VICE PRESIDENT OF DBI

large corporate members. That is why our most recent focus-series on Dbl's social media showcased Dbl's large corporate members. And that is also why this Dbl Review is somewhat of a special edition.

It introduces you 10 of our large corporate members. When we started showcasing them, there were 12, and during the focus-series, 2 small corporate members decided to take on more responsibility and become large corporate members.

Of course, this special edition of the Dbl Review is a form of saying THANK YOU to all

of them and, moreover, to ALL members of Dbl.

There is more to this edition: News from the next World Conference in Ottawa, Canada, news from the Networks, a couple of new excellent research articles and a fabulous interview.

The most important thing, however, which was and remains, is our global network, our connection and collaboration – despite all the problems, challenges, injustices, inequalities, conflicts, wars, disasters, and pandemics in this world. Together we are strong!

Save the Date! The 18th Deafblind International World Conference



**GLOBAL
CONNECTIONS**
18th International World Conference
July 22-28, 2023 🇨🇦 Ottawa, Canada



**CONNEXIONS
MONDIALES**
18ième conférence mondiale internationale
22-28 juillet 2023 🇨🇦 Ottawa, Canada

Save the date! The 18th Deafblind International World Conference is coming to Ottawa, Canada from Saturday, July 22 to Friday, July 28, 2023!

With the theme of Global Connections: The Future in Our Hands, the conference will be a hybrid event, which means you can attend either in person or virtually!

The objective we hope to achieve is to connect with more people than ever before. As more information becomes available you can stay informed by visiting our social media channels and our website at deafblindnetworkontario.com.

Canada welcomes you to join us in our beautiful national capital, Ottawa, Ontario, in 2023. Let's stay connected, the world is at your fingertips.

Supporting Tactile Cognitive Potentials: the TWMS Supervisor Training Course

The first supervisor training course on the Tactile Working Memory Scale (TWMS) is a fact. The course was organized by the Nordic Welfare Centre in 2021 and consisted of three online webinars and a three day “in-person” seminar which took place in Copenhagen, Denmark. The TWMS training course were attended by 16 professionals from 8 European countries (England, Scotland, Ireland, France, Sweden, Denmark, the Netherlands, and Norway).

Jude Nicholas (Norway), Annika Johannessen (Norway), Trees van Nunen (the Netherlands) and Maria Creutz (Sweden) were members of the scientific committee responsible for the program and content of the training course.

Content and aims

The content of the course was mainly based on the TWMS manual and scale (Nicholas, Johannessen & van Nunen, (2019)). The participants were introduced to the theoretical components of the TWMS and were provided with professional skills to identify, assess, and promote tactile sensory-perceptual, cognitive, and social cognitive potentials and strategies in people with congenital deafblindness. All participants who had attended the supervisor training course received a certificate.

The supervisor training course fulfilled two main aims. Firstly, the seminar addressed the practical application of the TWMS which ensured accurate administration, item scoring and interpretation of the behavioural manifestations of each item. Furthermore, specific tactile learning strategies that revealed learning growth were highlighted. Secondly, the role of a TWMS supervisor and guidelines on how the supervisor could instruct supervisees on the application of the TWMS were emphasized.

JUDE NICHOLAS

NORWAY

ANNIKA JOHANNESSEN

NORWAY

TREES VAN NUNEN

THE NETHERLANDS

MARIA CREUTZ

SWEDEN

During the training course, each individual participant or pair of participants were able to present and share their assessment cases and were supported to write a short case report. These warranted opportunities for the participants to share experiences and

Participant reviews

The participants had expressed that they had gained knowledge about the bodily-tactile modality and had learned how to apply the scale. Comments included the following: “Really solidified our knowledge around pertinent theoretical frameworks and learning strategies”; “We have learned to see tactile potentials from a cognitive perspective, in addition to a communication perspective”; “We have learned how to use the scale which helped us to systematically assess tactile functions and precisely discover potentials and areas of intervention”; “The assessment is about optimising skills and shift in focus of intervention within a dyad or scenario rather than assessing ability consistently”; “Refreshed our thinking about the level of the partnership being of utmost importance, not assessing and “scoring” the person, but the partnership-dynamic approach”.

The first TWMS supervisors

At the end of the training course a pool of TWMS Supervisors was established with the purpose for participants to support each other in the role as supervisors. A chairperson (Helle Buelund Selling, Denmark) and a co-chairperson (Marga Leefkens - van den Broek, the Netherlands) were selected from the group. By helping each other during the assessment process and by sharing own experiences, it would be possible to become more confident in using the scale and supervising other colleagues and staff.

The next TWMS supervisor training course is scheduled to take place in 2022.

Nicholas, J. T., Johannessen, A. M., and van Nunen, T. (2019). Tactile working memory scale: a professional manual. Sweden: Nordic Welfare Centre.

For further information regarding the scale or the TWMS supervisor-training course, please visit the website of the Nordic Welfare Centre.

intervention ideas. Both assessment case presentations and case reports clearly showed the commitment of the participants to their TWMS projects, with respect to individual vulnerabilities, competencies, and potentials of the person with congenital deafblindness.

The participants also expressed that they intend to use the TWMS in the future and they would be involved in staff training. Comments included the following: “We want to share the knowledge and application of the scale through supervision groups in our organization”; “Very excited to cascade this knowledge out across, which may help us to describe deafblindness in our country and promote our cause further”; “The scale has useful applications for other groups also, ASD, PMLD etc.”; “Share outcomes of validity studies on the scale to support uptake with professionals who require hard science evidence base; “We are excited to tell our colleagues about the scale. We are also optimistic and that by using the scale we could make a difference in the lives of people with congenital deafblindness”.



The new TWMS supervisors proudly with their certificates in Copenhagen, Denmark

Inclusive Education for Learners with Multisensory Impairment: Best Practices and Research Priorities

A new book entitled **'Inclusive Education for Learners with Multisensory Impairment: Best Practices and Research Priorities'** published by Open University Press, McGraw Hill. The author is **Dr Leda Kamenopoulou**, Associate Professor at the Department of Psychology and Human Development, IOE, UCL's Faculty of Education and Society (University College London), and member of Deafblind International and the Dbi Research network. The book argues that given the current global agenda, urgently calling for inclusive and equitable quality education and lifelong learning opportunities for all, it is paradoxical that in the vast body of literature on inclusive education very little attention has been paid to learners with the most complex needs, for whom inclusion in education can be very challenging to achieve without bespoke strategies, flexibility and creativity. This book aims to address this gap, by bringing together theoretical literature, the latest research studies, and

a synthesis of best practices and effective educational strategies. The specific objectives of the book are to: 1) expand the understanding of inclusive education and advocate for a focus on the 'quality of provision', 2) raise awareness and contribute to the current knowledge-base about deafblindness, and 3) present evidence and practice-based strategies for including deafblind learners in any educational setting. With illustrative case studies, tools, and bespoke activities, this book promises to be a much-needed resource for student teachers, professionals, post-graduate researchers and academics in the field of deafblindness, sensory and complex needs, but also all those interested in making inclusive and equitable quality education a reality for all, and not just some. If you are eligible, (working in Education internationally), you can request a free review copy through the [McGraw Hill website](#). You can read more about Leda's other work and research by visiting her [online profile](#).

YOU CAN REQUEST A FREE REVIEW COPY THROUGH THE [MCGRAW HILL WEBSITE](#)

Baptism and Launch of the Deafblindness Collection: Practical Guide to Usher Syndrome

MARÍA LUZ NERI DE TROCONIS

SOCIEVEN, SORDOCIEGOS DE VENEZUELA, A.C. (DEAFBLIND OF VENEZUELA), DIRECTOR GENERAL, THE 17TH SOCIAL INVESTMENT FUND OF VENEZUELA SIN LÍMITES, PROJECT COORDINATOR, DEAFBLINDNESS STUDY GROUP OF ICEVI LATIN AMERICA, COORDINATOR

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Practical Guide to Usher syndrome, Deafblindness Collection.

Authors: María Luz Neri de Troconis and Nelly Ramírez.

Co-authors: Paula Arreaza and Tany Fonseca.

Editors: Elaine Moya, Katerin Arrieta and Laura Gordon Graphic Design.

Layout: Neri Design Group.

Video Production Team: UDEF.

Photography: Yndira Diaz Maluenga.

Talents with Usher Syndrom: Amarilis Sánchez, Yulianny Fajardo.

It is a great honor for us, at SOCIEVEN, that this has been achieved thanks to the contribution of Venezuela sin Límites (Venezuela without Borders), DIGITEL, and Una Sonrisa a Tu Cuenta de GAMA (A smile to your account of GAMA), through the project Knowing my Deafblindness due to Usher Syndrome.

On Tuesday, July 12, we carried out the baptism of the Practical Guides of Usher Syndrome. A Five Senses Product, developed at the National Center for Social Action for Music in Caracas, Venezuela.

Here are the words of Maria Luz Neri de Troconis,

Dear everyone, it is a great pleasure to be performing the baptism ceremony of this material today. The SOCIEVEN team has been dreaming and wishing for a long time to achieve it and we've got the resources thanks to the confidence and trust of our allies. Being here today, we have a wonderful opportunity to express them our endless thanks.

These guidelines address the challenge we presented to the Social Investment Fund:

Individuals who are deafblind due to Usher syndrome require self-recognition and understanding of their condition to be able to manage it and to have opportunities for their independent development at home and outside it, to be socially included and to have accessibility by means of reasonable accommodations. Thus, we will empower them to improve their quality of life through the resources and activities that will be developed for them, by their families, professionals, their peers, and the community in general.

The situation of confinement due to the pandemic affected adolescents, youth and adults who are deafblind due to Usher syndrome because of isolation. And their situation deteriorated due to the changes in their family dynamics and the lack of basic education, food and health services. Their marked confinement within their homes and communities is evident.

The developed project is a wonderful one, and its scope is endless. We achieved a unique product, the Practical Guides of

Usher Syndrome in digital format, printed format, videos with sign language interpretation and written text. All these with the necessary accommodations and adjustments for the individuals who are deafblind due to Usher syndrome, the individuals having tunnel vision, hearing loss, vision loss, and many other different conditions, to make it accessible to them. It will reach them either in Braille or audio according to the programs they have in their special electronic devices. And it will allow those individuals who do not have Usher syndrome, enter their world to understand it and participate in a true responsible inclusion system.

As a result of creation of these three guides, we have the following products:

- A Practical Guide to Usher Syndrome, which consists of three digital documents.
 - Nº. 1: I Know My Deafblindness due to Usher Syndrome.
 - Nº. 2: What We Do to Improve Our Life and Accessibility.
 - Nº. 3: Understanding the Genetics of Usher Syndrome.
- 3 printed guides.
- 3 Braille guides which will be issued in the future.
- Four Videos: I Know My Usher Syndrome Deafblindness, a Testimonial Video.
- The set of 3 Practical Guides of Usher Syndrome in accessible format (audio, interpretation in Venezuelan sign language and captioning).

Thanks a million from SOCIEVEN, from the individuals having Usher syndrome in the country, professionals, families, the community of deafblindness, individuals having hearing and vision loss, Venezuelan educational and health institutions. When we talk about the individuals with disabilities, not only they (as our protagonists) must be present in every act which involves them, but also the institutions like yours that join us. That's because if we work together, we achieve a lot more

for the benefit of inclusion, accessibility, and rights of people with disabilities in Venezuela.

It should be emphasized that the experience of developing this magnificent, unique, and original material has been a wonderful, enriching, and revealing experience. When we initiated this project aimed to provide access to individuals having Usher syndrome through digital booklets to be used in visual devices and e-learning platforms, we saw it as something simple with a quite clear goal.

The experience and the search for real accessibility and responsible inclusion through products that truly meet this challenge was enormous, with many phases and stages: researching, reflecting and discussing, meeting, consulting with experts, elaborating the contents and validating them, an accessible design and the second validation to ensure the accessibility of the design. These included photo sessions, video sessions, editions, and revisions plus new validations, meticulous organization, and discovering that there are no materials of this kind in the whole world, neither on Usher syndrome nor with respect to true accessibility.

Thank you very much for your advice and time. I remember Margarita Rodríguez and her advice: the texts should start in the left corner at the top; Verdana font is the one we read best; if you place a title or text in the middle, it will be passed by and will not be read; hence, all the texts start on the left. When we indicated that the design of the guide should be against dark background with good contrast and that the text should be written in Verdana font, Neri Design Group with Gabriela Neri and Joyce did it: everything centered and impeccable. In attempts to make them understand, we insisted that they had to put everything starting on the left. They repeated that it would not look nice and we explained that the individuals having Usher syndrome would see it and that they would not lose any information, and that in addition, some photos had to be edited so that the user could distinguish a person in the dark, and each photo should have a white frame so that it would stand out.

And talking about the photos taken by Indyra Diaz with mega production to make each required photo in Café Arábica and at the venue of the function, the Casa Modelo de la Sordoceguera (Deafblindness Model House) and the experience of the videos with José Gregorio Morales, it included the following: planning the recording, finding the guide interpreters, preparing a place to sit, giving the time to each individual who is deafblind (talent), and an accessible edition; plus the recordings in sign language of all these to be included in each video. For all of them the editing was the hardest part: put more light, more to the left, frame the photo in white, put a blue background to the text and write it in white letters and so on. What patience from all of them! Thank you so much for perfectly interpreting what we were looking for. A true collaborative work.

And what can I say about the team of authors, editors, and support people? Let's put this, let's remove that, write and recheck, send messages to designers, make corrections. Everyone was organized and showed enormous patience from the development of content and a prototype ready to pass to the design phase. And I remember when one day when we thought everything was ready for the final stage, I told them, "This is not yet what I'm looking for, you have to add more description to the photos and more details about its content". And we went back to work on this. The girls of the team wanted to kill me, but I knew what we had to achieve and we did it. Thank you SOCIEVEN team, you are a blessing!

As a result, we developed a unique and innovative product, which has been achieved with the main contribution of five empowered women having Usher syndrome, their clear ideas and a model of quality of life. We are extremely grateful to them! We have also enjoyed working with them because they are our funny and intelligent USHERINAS, we love them so much.

We went all the way to the island of Margarita in the state of New Esparta to provide them with activities, medical evaluation, operation, counseling and the presentation of the new guide in digital format to measure the

effectiveness and the employment requirements to carry out the activities in e-learning and other training platforms on their reception.

We know that the practical guides on Usher syndrome elaborated by SOCIEVEN will be totally useful for people with Usher syndrome in Venezuela and the region and will also be a model of a new way of creating accessible and inclusive products for people with disabilities.

I invite all of you to use and share your I Know My Deafblindness due to Usher Syndrome digital kit, as it will be fully accessible to every person with Usher syndrome in our country and more countries, their families, professionals, education and health institutions, doctors in general and especially ophthalmologists and otolaryngologists, speech therapists and the community in general as a door to achieve responsible inclusion. And I especially invite organizations working with the individuals who are deafblind, communities of the individuals having hearing loss,

and individuals having Usher syndrome to join the campaign to disseminate this material.

Register through the link to get this digital kit: https://docs.google.com/forms/d/e/1FAIpQLSfQmlqzfsDPd4qtInQRZY65FfaWBma1wilOcjVwSj6UUIOV0Q/viewform?usp=sf_link

You can find this link in the bio of @socieven or write to socieven@socieven.org

You can follow us on Facebook [SOCIEVEN_Sordociegos de Venezuela](#), as well as on Instagram [@socieven](#)

It is important for us to get to know each of the people and institutions that will receive this material and about its proper use as a pedagogical tool for dealing with the individuals having Usher syndrome. Thank you very much.

A Practical Guide to Usher Syndrome is a national and international reference in the approach to the individuals having Usher syndrome. Everybody is waiting for it.

News from the Anne Sullivan Foundation, Ireland

DEIRDRE LEECH

M.ED, DEAFBLIND
CONSULTANT,
ANNE SULLIVAN
FOUNDATION,
IRELAND

Greetings from rainy Ireland! We continue to work with individuals around the country through our Outreach and Advocacy programmes. We were sad to bid farewell to Heather Colson-Osborne after 15 years in the Anne Sullivan Centre, who has made the move back to her home in the UK and is working for Seashell Trust. Many of you would have met Heather at the DBI Conferences in the past, both in person and online! We welcome Sorcha Nallen into Heather's role in Outreach, covering the east of the country. Sorcha is happy to dive in to her role after being in the Anne Sullivan Centre

We have been lucky to receive another year of funding from the Late Late Toy Show / Community Foundation for our Deafblind Literacy Project. Last year, we trained hundreds of people in the community including Transition Year students to create tactile books so that students in special schools can have access to books that appeal to their sensory needs. This year will also focus on libraries and training for those who will be reading the books with the children. It is a very exciting project.

We have also received lottery funding which we are putting towards an assistive technology lending library. The hope is that individuals who are deafblind can try out devices before purchasing them to see if they like them before making a big investment. The library will range from everyday household items to communication equipment.

We continue to run our Advocacy groups in Dublin and Cork for adults in the community who are deafblind to connect, talk about issues, and

have some social time. We hope to run more activities in 2023 now that restrictions are gone!

The residents at the Anne Sullivan Centre in Dublin continue to learn in their homes and community, try new experiences, celebrate milestone birthdays, and go on amazing trips with their staff. If you wish to learn more about what we do in our Residential, Day, Outreach and Advocacy Services, please go to www.annesullivan.ie

If anyone reading this who is part of the DBI community anywhere in the world wishes to engage with us on any of the following topics, we would love to connect with you! Some of our latest interests are: assistive technology, events for deafblind adults to meet up, housing options for deafblind adults in other countries, rights of individuals who are deafblind, and ensuring access in the community. We would also love to connect with other smaller countries like ourselves. Get in touch with us at info@annesullivan.ie



Intervener/or Community of Practice

A group with representatives from organizations involved in intervener(or) training across the United States and Canada (members listed below) came together for virtual meetings to network and learn from one another. As members shared their experience, strategies, successes, and obstacles, the lack of opportunities for interveners(ors) to meet and engage in professional development were found to be common issues. The group came to be known as the Intervener/or Community of Practice. In time, the group may explore becoming a Dbl Network focusing on interveners(ors), intervention, and intervener(or) training.

The focus of the group quickly pivoted from sharing information to organizing professional development and networking opportunities for interveners(ors). The group decided to call each event a, "Munch n Learn," to capture a casual atmosphere for coming together. Participants were encouraged to bring a snack or their lunch depending on their time zone. A few virtual events have already been held. Each Munch n Learn has an identified topic of interest for interveners(ors) and includes one or more short presentation(s) and opportunities for small and large group reflection and sharing. Intervenors(ors) from the U.S., Canada, the United Kingdom, and South America have participated. Events are conducted in English and American Sign Language (ASL).

The first Munch n Learn focused on experience books. Intervener(ors) from the U.S. and Canada were recruited to show an experience book that they developed for a

person who is deafblind. After the presentations, participants broke into facilitated small groups to discuss the presentations, share, and apply what they learned. The second event included a simulation that required participants to create a craft project. When the simulation was complete, interveners(ors) were divided into moderated small groups to apply what they learned to predetermined scenarios. Intervenors(ors) came back together for a short presentation and then divided back into their small groups to discuss how to make accommodations for people who are deafblind. The third Munch n Learn included short presentations by interveners(ors) from the U.S. and Canada who presented on the types of support that they provide for a person who is deafblind. After the presentations, interveners(ors) were broken into facilitated small group sessions to discuss the role of the intervener(or). Each group was asked to develop an "elevator

pitch” (a description lasting a few seconds, or the time it takes to go a couple of floors on an elevator) on their role as an intervener(or). A volunteer from each group reported out to the larger group so that everyone could benefit from one another’s ideas. Participants created a word cloud to capture some essential elements of being an intervener (see image below list of members). At the end of the third event, there was time for interveners(ors) to introduce themselves and share something about their work.

A fourth Munch n Learn is hold on November 5, 2022, with a focus on the lived experience of a DeafBlind person who has had the support of an intervener(or) and the

perspective of a parent whose child has had the support of an intervener(or). The event includes small and large group discussions to reflect on and process the content of the presentations.

While the membership of the group started with people who are invested in some aspect of intervener(or) training, the goal is to find and mentor intervener(ors) to take the lead in planning, hosting, and presenting the virtual events. Intervenors(ors) interested in learning more about upcoming events can find the group on Facebook [using this link](#). Please note, the Munch n Learn virtual events are only for trained interveners(ors) and students studying to be interveners(ors).

Planning Team Members:

Kristi Probst, Ed.D. – National Center on Deaf-Blindness (NCDB)

Beth Kennedy, Ph.D. – DeafBlind Central: Michigan’s Training and Resource Project and the DeafBlind Intervener Training Program at Central Michigan University

Marilyn Likins, Ph.D. – National Resource Center for Paraeducators, Related Service Providers, and Intervenors (NRCPara)

Ritu Chopra, Ph.D. – Paraprofessional Resource and Research Center (PAR2A)

Leanne Cook, M.S. – Paraprofessional Resource and Research Center (PAR2A) and Columbia Regional Inclusive Services

Ira Padhye, M.Ed. – Virginia Project for Children and Young Adults with Deaf-Blindness and

Partnership for People with Disabilities at Virginia Commonwealth University

Linda Alsop, M.Ed. – Intervener Training Program at Utah State University, National Intervener and Advocate Association (NIAA)

Theresa Tancock – Canadian Deafblind Association – British Columbia Chapter (CDBA-BC)

Carolyn Monaco – Canadian Deafblind Association (CDBA) Board of Directors, Deafblind International (DbI)

Linda Mamer, Ed.D. – Canadian Deafblind Association – British Columbia Chapter (CDBA-BC)

Laura Aguiar – Intervenor Organization of Ontario

The Ibero Latin America Network Report

Ongoing contributions are still required for uninterrupted services to continue.

Throughout this year The Ibero Latin America Network has been presenting a series of webinars focused on informing, teaching, and giving clarity on the various aspects of deafblindness.

Approximately 2 hour webinars are presented monthly on Saturdays. Even though the webinars are focused on those directly involved, they are also open to anyone interested in gaining insight into deafblindness. A variety of themes are offered ranging from medical research to testimonials from real life experiences.

With our members' diversity in mind, we offer a multitude of language choices, translation options including sign language interpreting and audio description of the slides and pictures. The participating staff, coordinators and IT technicians are all professionals and most of them contribute on a voluntary basis.

The themes presented are as follows:

- Maria Margarida Rodriguez – ethics;
- Maria Margarita Rodriguez – clubs for the individuals who are deafblind in Canada;
- Challenges of CHARGE syndrome:
 - Dr. Tim Hartshorne – professional and family point of view;
- Pam Ryan, MS – scientific point of view;
- Denise Teperine – intervention;
- Márcia Borges – mother;
- Eduardo Ruas – intervention at school;
- Célia Leão, State Secretary – rare syndromes;
- Sonia Margatira Villacres Mejia – good practices as an individual who is deafblind;
- Dr. Gabriela Rovezzi – how to act in CVI;
- Md. Dr. Marta Lucia and Md. Dr. Juliana Sallum – Usher syndrome from the medical perspective;
- Living with Usher Syndrome:
 - Carlos Jorge – an individual having Usher syndrome married to a woman having Usher syndrome and athlete, Brazil.
 - Eulália – an individual having Usher syndrome and an advocate of the rights of people with disability, Brazil.

LAURA LEBRE MONTEIRO ANCCILOTTO

IBERO LATIN AMERICA NETWORK, GRUPO BRASIL DE APOIO AO SURDOCEGO E AO MÚLTIPLO DEFICIENTE SENSORIAL, VICE PRESIDENT, SÃO PAULO, BRAZIL

LAURARABBIT71@GMAIL.COM

NEWS FROM NETWORKS

- Camila – mother having Usher syndrome, Brazil.
- Gerardo – an individual having Usher syndrome in the workplace for more than 25 years, Colombia.
- Nelly – an individual having Usher syndrome and researcher, Venezuela.
- Clarice Nunes – inclusive education, which is the last one planned for the current year.

This series of webinars has been successful in helping us increase awareness, and has expanded our membership from 30 to more than 500 members, yet there is still much to do and our plan for the coming year is to continue offering informative webinars. Our goal is to increase our membership internationally with special emphasis on Portuguese speaking countries in Africa and Asia.

If you want to become a member or support the Ibero Latin America Network, please contact us at ximena.serpa@gmail.com

Deafblind Education Network

This announcement concerns a new network named Deafblind Education Network. The focus of this network is the following: Teaching professionalism, separated from social care.

This network saw the day of light at the Nordic Welfare conference in Tampere, Suomi Finland, on September 20, 2022, when a presentation was given by Mr. Anders M. Rundh, founder of this network.

As highlighted in the presentation, we see an urge for this network, as the materials within the field of deafblindness are focused on a very minimized group of people. With this

network we enable educators to ask, to give answers, and to inspire each other, no matter where in the world they are.

On behalf of this network, Mr. Anders M. Rundh applies for a workshop at the world conference in Canada in July, 2023 to meet, discuss and look into the future of Deafblind Education Network and teaching professionalism.



Learn more:

<https://skema.rn.dk/servlet/com.pls.morpheus.web.pages.CoreRespondentCollectLinkAnonymous>

Technology Network

The Technology network held an online network meeting on October, 3. This meeting was dedicated to sharing projects, ideas and news between the network members. 35 members from different parts of the world (Europe, Northern America, and Africa) attended the meeting.

Together, we presented and discussed a diversity of issues concerning technology that could be helpful for the individuals having vision and hearing impairment. In this news update, we will share the topics that were discussed.

- **Project Termability.** This 8-month project was dedicated to clarifying the terms of service agreements and data privacy concepts of websites and/or social media in plain (English) language, video and ASL. People with sensory challenges were included in the project so that the developed tool would be as accessible and useful as possible.
- **Telehaptic 7th sense device.** This is a helmet for the individuals having vision and hearing loss which provides haptic and thermal feedback messages to the head. This enables the wearer to feel objects which are beyond the reach of their arms. The helmet is now at the stage of a prototype but will be hopefully released in 2024.
- **Eikholt ICT team.** Members of this team have presented how they provide person-centered rehabilitation services to the individuals having vision and hearing loss. They work in an interdisciplinary team and provide consultation, teaching (courses), conferences and seminars, and information sharing.
- **INCLUDE-network and the MuseIT project.** The INCLUDE-network fosters inclusive studies, inclusion, participation, accessibility, and equality. The center is engaged in research, innovation, policy studies, events, and activities. The MuseIT project is an international project in its starting phase. It aims to co-design and develop technologies that improve accessibility to cultural heritage beyond the visual and auditory senses.
- **Feel the physics.** The process of archeology is usually presented visually to the public. How can we present images of uncertain data collections of measurements in an accessible way to people who are visually impaired? Would it be possible to present these data in a tactile form? The project first started with laser cuttings in wooden boards making it tactile. Suggestions from the network members were 3D printing, and the Stanford University shapeShift.
- **IFA Trade Fair.** Some network members have attended this fair in search for the latest developments in haptic

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NEWS FROM NETWORKS

technology. There, we have seen the Actronika haptic vest, the Therabody massage product, the Ybrush toothbrush and the Hapticore buttons, and we have discussed these devices at the network meeting.

After the presentations, we discussed how we would like to meet during the next Dbl world conference in Canada and what other activities we envision for the network. We decided upon a hybrid session during the conference with presentations of the network members. Furthermore, it was suggested to discuss challenges that we come

across in finding technical solutions for the individuals with vision and hearing loss. This is what will be targeted at our next online network meeting in the spring of 2023.

If there is anything in this report that interests you, please get in touch with the network coordinator Mijkje Worm mworm@bartimeus.nl We'd like to emphasize that the network is open for everybody who is interested in technology for the individuals with vision and hearing loss. This includes those who do not feel experienced (yet) in this topic! You can sign up at Dbl's webpage or contact the network coordinator directly.

Communication Network

On June 21 we organized an international symposium on deafblindness from the UG Institute for Deafblindness at the University of Groningen with very interesting presentations about communication.

There were, among other topics: protactile communication by Lisa van der Mark, research by parents of the individuals having congenital deafblindness, Rosemarie van den Breemer and Liliast Liston, communication and life-long learning, academic volumes for Oxford University Press by Walter Wittich and Tim Hartshorne, video-analysis and communication from a dialogical perspective by the Groningen Study group on Diversity of Communication, research and focus for the future by Saskia Damen, and new perspectives on deafblindness by Marleen Janssen. These presentations are recorded and you can view them in the near future at <https://www.rug.nl/gmw/pedagogical-and-educational-sciences/research/ugidb/>

Our specific activities for the rest of 2022 and coming 2023 up till the Dbl World conference in Ottawa, Canada in July next year, are as follows:

- **Organizing on-line webinars**, 2 times a year, in November 2022 and in April 2023, on communication, especially focused on parents and family members of children and adults with congenital deafblindness; with interpretation in Spanish, Portuguese and sign language. The next webinar takes place on November 17 and is entitled Tactile Communication
- and the Use of Different Hand Positions. During the webinar there will be practical activities trying out different hand positions. The webinar is inspired by the work of Barbara Miles and Michael Cyrus. It is presented by Helle Buelund Selling, member of the Nordic Network on Tactile Language and Development, and consultant at the Center for Deafblindness and Hearing Loss in Aalborg, Denmark. See the flyer on our website;
- **Preparing the preconference** in Canada in July, 2023, which will last for 2 days and will be divided into 4 parts aimed at the individuals who are deafblind, professionals, families, and researchers;
- **We are working on three different book projects:**
 - The Groningen Study group on diversity in communication (which are the founders of this Communication Network) is working on **a new book on video analysis and communication from a dialogical perspective**.
 - Together with the large number of members of the Communication Network and the Research Network we will work on **two academic volumes** for the Oxford University Press, and **one**

**MARLEEN
JANSSEN**

DBI
COMMUNICATION
NETWORK

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NEWS FROM NETWORKS

professional volume. One book is focused on the assessment and intervention of communication in children and adults who are deafblind. This book on communication will be finished in December 2023 and published in 2024.

- Composing and publishing **an overview book of 40 years of communication articles** in the Deafblind International Review magazine which will be finished in 2023.

We have expanded the organizing team of our Communication Network, and now, besides Meredith Prain from Australia, Helle

Buelund from Denmark, and myself, it consists of Saskia Damen from the Netherlands and Steve Rose from the UK.

And if you are interested in this Dbl Communication Network you can become a member by visiting the website of Deafblind International

<https://www.deafblindinternational.org/about-us/become-a-member/>

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

Family Network

Background

The Family Network of the DbI was created in 2022, being a family network that aims to establish meeting mechanisms between the families of the individuals having deafblindness and multiple disabilities worldwide in order to develop strengthening strategies, generate proposals and comprehensive care for each of the members of the family nucleus, achieve the recognition and legal visualization of the specific needs of families of people with disabilities, especially in the area of severe and complex disabilities such as deafblindness and multiple disabilities.

The initiative originated from the mind of mothers, leaders of families in their countries and founders of institutions that guarantee the social inclusion of their children and seeks the integral development of the individuals with multiple disabilities and congenital deafblindness. As it has been said, Aurea Soza from Argentina, María del Carmen Schleske from Mexico, and Massiel Requena from Venezuela, are founding members and directors of Sullai, Cemdys, and Ven Camina Conmigo to Build Inclusive Families, non-profit organizations, respectively. They provide programs in favour of people having multiple disabilities and deafblindness in Argentina, Mexico, and Venezuela.

Three women, three Latin American countries with a common need to provide effective specialized care responses for their daughters with congenital deafblindness, Rupe, Dubhe and Barbara who represent the inspiration and motivation to generate quality services, promote

inclusion and attend to the individuals with deafblindness and multiple disabilities using the biopsychosocial approach.

The Latin American meeting of the year 2010 sponsored by Perkins International and directed by our mentors and friends, Steve Perrault and Graciela Ferioli, allowed us to get to know each other personally and create an endearing bond between us. However, due to pandemic, until 2020 we have been formally organized as a Network of Leading Families in Latin America and the Caribbean for the inclusion of people with sensory challenges, intellectual and multiple disabilities, taking up what had remained in Córdoba, Argentina in 2010.

We have been working intensively to strengthen our ties and determine the formal structure of the network for 2 years. Excactly at that moment our consultant Graciela Ferioli invited us to go one step further and propose to the Deafblind International (DbI) to create the Family Network which was established in July of this year 2022, reaching an important and transcendental goal towards the recognition for the families of the individuals who are deafblind.

Our current challenge is to establish strategic alliances with families of the individuals having deafblindness and multiple disabilities and with professionals worldwide with the purpose of conceiving collaborative teams that facilitate the care, training and vindication of families, consenting an effective inclusion of the individuals having deafblindness and multiple disabilities in the world.

MASSIEL REQUENA

COORDINATOR
(PRESIDENT)

AUREA SOZA

FAMILY
COUNSELING
(TREASURER)

MARIA DEL CARMEN SCHLESKE

EXECUTIVE
SECRETARY

Objectives

- To design and establish the structure of the Family Network;
- To build awareness of the Family Network among families and professionals;
- To incorporate families and professionals into the Family Network;
- To promote and generate collaborative teams of families on a country-by-country basis;
- To organize and carry out virtual and face-to-face activities;
- To generate consultative documents on the needs, systems or mechanisms of care aimed at families;
- To produce informative material for family matters on social networks;
- To establish alliances with professionals in the area to generate specific training of interest to the members of this network;
- To promote advocacy mechanisms to achieve legal recognition with respect to the specific needs of families of the individuals having deafblindness and multiple disabilities.

Mission

- To establish a Worldwide Network of Families of the individuals having deafblindness and multiple disabilities, capable of conceiving social and legal changes that allow integral inclusion for the individuals with disabilities and their families without any discrimination.

Vision

- To consolidate and strengthen families of the individuals having deafblindness and multiple disabilities worldwide, forming collaborative teams in a significant number of countries with the purpose of generating social and legal changes.

For us it is a pride and a great commitment to be the founders of this network, and we have all our will aimed to lay the solid foundations so that all the families of the DBI had a space to grow, give and receive information, strategies, accompaniment, and support that facilitates the path and promotes the integral well-being of the individuals having deafblindness and multiple disabilities as well as of their families.

Able Australia

Able Australia is committed to deliver better days every day to the individuals who are deafblind and work collaboratively to support this community.

We are a proud large corporate member of Deafblind International, recognising our heritage and support of the deafblind community. Able Australia was established in 1967 in Melbourne, Victoria, Australia, originally as The Victorian Deaf Blind and Rubella Children's Association, by families of children born with congenital Rubella syndrome.

Able Australia has expanded to provide services to hundreds of people with disability across Australia. Our Deafblind Services team provides assistance, coordination, and communication guide support to the individuals who are deafblind and live independently in the community.

Our Centre of Excellence – Deafblind collaborates with universities and other organisations to undertake research aimed at developing evidence-based best practice in service delivery for the individuals who are deafblind. The Centre of Excellence – Deafblind also delivers training, provides

consultancy, and undertakes advocacy activities.

Able Australia's experienced Allied Health and Positive Behaviour Support Teams provide services to the individuals who are deafblind including Deafblind Consultancy.

As a leader in the field of deafblindness, Able Australia truly values the opportunity that our ongoing membership of Deafblind International provides. Through Deafblind International's broad global networks, Able Australia can share the expertise, best practice research, and range of resources developed by our team and the deafblindness community internationally.

Together, we will make a real difference in the lives of the individuals who are deafblind in Australia and around the world.

Learn more about Able Australia and our Deafblind International membership in our [video](#).

LINK:

[HTTPS://
ABLEAUSTRALIA.
ORG.AU](https://ableaustralia.org.au)

VIDEO:

[HTTPS://YOUTU.BE/
RZZSITPCCSQ](https://youtu.be/RZZSITPCCSQ)



SensesWA

LINK:

<HTTPS://WWW.SENSESWA.COM.AU>



SensesWA is a not-for-profit organisation in Western Australia. We have been providing disability services to the Western Australian community since 1895, where we began as the Western Australian Industrial School for the Blind.

We are located across metropolitan Perth and regional western Australia and we provide a wide range of therapy, Independent Living Options, Support Coordination and Community Support. We have a dedicated team of Deafblind Consultants who work across the lifespan with people with dual sensory disability. We are the only service in Australia that specialises in working with deafblind children.

The Deafblind team at SensesWA consists of Occupational Therapists, and Orientation & Mobility Specialist, Orthoptist, Physiotherapists, Speech Pathologists, Social Workers, and Deafblind Consultants. We provide services to our clients in their homes, workplaces, schools, and community locations, working

alongside our clients to help them achieve their goals.

In June 2022, SensesWA hosted the 11th National Deafblind Conference, bringing together professionals and people with deafblindness from across the country to share knowledge and connect face-to-face again. This was a fantastic event, hosting 119 registrants in Perth and many more from around the world streaming online.

The Deafblind team at SensesWA are passionate about connecting deafblind people in Perth to supports, resources and their community to enrich the quality of life of our clients. We are proud to be affiliated with Deafblind International, who share the same passion for connection and knowledge sharing on a global level.

The National Resource Center for Deafblindness

The National Resource Center for Deafblindness (Nkcdb in Swedish) has been acting under the National Swedish Board of Health and Welfare since 2013 but has worked under the Mo Gård foundation since 2003. The overall goal is to develop awareness of deafblindness and to share and distribute information in various forms and contexts all over Sweden. Another goal is to outline long-term strategies to create sustainable and nationwide support for people with congenital/early or acquired deafblindness of all ages. Furthermore, it is of great importance to observe research and development and make the results known and accessible. So far, there are 10 employees and almost 20 consultants working with Nkcdb.

The National Board of Health and Welfare has concluded a new agreement with Nkcdb for the period of 2023 – 2027, covering the following areas:

- To provide expert assistance to the regions in their activities of organising support for the individuals who are deafblind and to other principals of relevant authorities;
- To collect, develop, and distribute information about deafblindness;
- To provide support in promoting systematic method development in the field of deafblindness;
- To cooperate with recognized target groups for further

development of courses and trainings in the field of deafblindness;

- To identify and promote the use of technology and services for the individuals who are deafblind to improve their access to information and communication;
- To set up forms of collaboration for in-depth user cooperation within the field of deafblindness regarding user participation in all parts of the assignment.

Mo Gård

The National Resource Centre for Deafblindness is a limited company owned by the Mo Gård foundation.

LINKS:

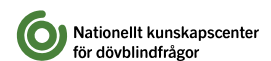
WWW.NKCDB.SE

WWW.MOGARD.SE

MEMBERSHIP FILM:

[HTTPS://YOUTU.](https://youtu.be/7XE7AHRFFCE)

[BE/7XE7AHRFFCE](https://youtu.be/7XE7AHRFFCE)



Nationellt kunskapscenter
för dövblindfrågor

LARGE CORPORATE MEMBERS

Mo Gård is a private knowledge and service group working within the field of communication and disability. The non-profit operations are carried out at 20 some locations in southern Sweden, offering accommodation

with special services for adults, daily activities, accommodation with special services for children and young people and individual programmes at upper secondary school level.



The staff at the National Resource Center for Deafblindness in Sweden, from left to right: Sofia Hansdotter, Helene Engh, Caroline Lindström, Monika Estenberger, Karin Jönsson, Linda Eriksson, Karen Catalán, Moa Wahlqvist, Eva Bökman, and Lena Göransson.

Lega del Filo d'Oro Onlus Foundation

58 years of commitment to the individuals with deafblindness and multisensory impairments

A precious thread that unites the individuals who are deafblind with the outside world. This is the concept that since 1964 has inspired the name and activity of the Lega del Filo d'Oro to the point of making it the most important reference point in Italy for assistance, education, rehabilitation, recovery, enhancement of residual potential and support in the search for the greatest possible autonomy for people with deafblindness and multisensory impairments.

The Foundation has its national headquarters in Osimo (AN), where the new National Centre was inaugurated in December 2017 and is scheduled for completion by the end of 2022.

The National Centre houses the Rehabilitation Centre recognised by the Marche region as a Special Unit for the Deafblind And Multisensory Impaired. It houses the Diagnostic Centre, which formulates global assessments and carries out early intervention, the Educational-Rehabilitation Services, which implement customised rehabilitation programmes through full-time and day hospitalisation, outpatient services and home treatment, the Medical Sector, and the Territorial Service.

The Documentation Centre and the Research Centre, which design, build and test methodologies

and support tools (e.g. assistive technologies) that enable users to interact with the environment and acquire their own level of autonomy, are also located at the national headquarters.

A specific training and continuing education service for staff and volunteers is also active, 651 employees and 377 volunteers respectively as of December 31, 2021.

Today, Lega del Filo d'Oro is active in ten regions with another four Residential Centres (for socio-medical interventions) and the annexed Territorial Services: in Lesmo (MB), Modena, Molfetta (BA), Termini Imerese (PA) and in the five Territorial Offices of Padua, Rome, Naples, Novara, and Pisa.

Every year the organisation assists around 950 users from all over Italy.

Lega del Filo d'Oro has always been committed to safeguarding the rights of the individuals who are deafblind and is working for the full implementation and improvement of Law 107/2010.

The organisation collaborates with numerous universities, it keeps contact with European Institutions and with national and foreign bodies and organisations; it has been part of Deafblind International from 1980 as a Large Corporate Member, and also of

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LINK:

WWW.LEGADELFILODORO.IT

MEMBERSHIP FILM:
[HTTPS://YOUTU.BE/DJJNJATOCN4](https://youtu.be/DJJNJATOCN4)



lega del filo d'oro

■ LARGE CORPORATE MEMBERS

the MDVI Euronet group (Multiply disabled visually impaired European Network). It also promotes numerous initiatives in the field of scientific dissemination.

The Foundation's activities are only partially financed by public funds, so the work carried out by the Communication and Fundraising Sector is fundamental.

The German Deafblind Consortium

Arbeitsgemeinschaft der Einrichtungen und Dienste für taubblinde Menschen in Deutschland

Members of the German Deafblind Consortium (AGTB) are institutions and competence centers for people in Germany with deafblindness or multisensory impairment. These institutions offer inpatient, partly inpatient, and outpatient services to affected people of all ages, their families, and caregivers.

The purpose of the AGTB is the collaboration on a subject-specific, organizational, and political levels. AGTB institutions command over the newest scientific insights and have more than 100 years of experience of working with the individuals who are deafblind in Germany. This has led to various publications and continuing education offerings within the field of sensory impairment.

The German Deafblind Consortium is a member of Deafblind International (DBI) as well as a member of the German Joint Expert Committee on Deafblindness and Multisensory Impairment (GFTB). We have a close network with related institutions, associations and federations throughout Germany, e.g. The German Association for Education of the Blind and Visually Impaired (VBS) and Leben mit Usher e.V. (Living with Usher syndrome).

What is deafblindness and multisensory impairment?

Deafblindness and multisensory impairment are disabilities of their own kind and not just a combination of vision and hearing loss. Since the respective compensatory sense fails or is impaired, deafblindness and multisensory impairment is different from the situation of a person having hearing impairment and additional disabilities. In many cases, even relatively minor disabilities of 2 separate senses, vision and hearing, result in severe impairments of overall development. And the deafblind-specific need for

support and thus the functional disability are crucial. Deafblindness and multisensory impairment are sometimes combined with other physical and mental disorders. Therefore, it is critical to consider the potentiation due to other existing disabilities and accompanying behaviors that may have an impact on functional hearing. The time of disability onset, whether it was before or after language acquisition, also has great importance for the development of the individuals having deafblindness and multisensory impairment.

LINK:

WWW.AGTB-DEUTSCHLAND.DE

VIDEO:

[HTTPS://YOUTU.BE/JP-WVYRQXWU](https://youtu.be/JP-WVYRQXWU)

AGTB

Sense

LINK:

[HTTPS://SENSE
INTERNATIONAL.
ORG.UK/](https://senseinternational.org.uk/)

VIDEO:

[HTTPS://WWW.
YOUTUBE.COM/
WATCH?
V=T8HBRBMXOMQ
&T=107S](https://www.youtube.com/watch?v=T8HBRBMXOMQ&t=107s)

Sense is a national disability charity supporting individuals who are deafblind or have complex disabilities in the UK. We believe [everyone should be able to take part in life](#), no matter their disability. Our work empowers people to communicate, experience the world and fulfil their potential. Our sister charity, [Sense International](#), is dedicated to supporting in eight countries worldwide.



Our story began over 65 years ago when two mothers who contracted Rubella during pregnancy gave birth to children who were deafblind. Faced with little support, they formed a group with families in similar situations to provide their children with opportunities to connect, communicate and establish friendship. In time, the group started sharing their skills and knowledge more widely and eventually became Sense.

Today, we support thousands of individuals who are deafblind or

have multiple complex disorders each year. We provide personalized services for children and adults and we offer expert advice to families and caregivers. We also help people facing social isolation and loneliness. On top of that, we campaign for the rights of the individuals who are deafblind or have complex disabilities.

Our international work started in 1994. We ensure that the children who are deafblind are identified as early as possible and enable individuals who are deafblind to

access healthcare, education, training and work, so they can thrive. Sense International supports people across 4 continents through locally registered organizations and our partners.

Sense and Sense International have a long history with DBI. We are proud to work with and support the activities of many member

organizations who are helping to create a better world for the individuals who are deafblind. We value the opportunity to learn from and share our own experience with other members, whilst striving to raise awareness of deafblindness as a unique disability and improve services for the individuals who are deafblind. Long may this collaboration continue.

Royal Kentalis

ESTHER VAN DIJK

DEAFBLINDNESS
AND COMPLEX
COMMUNICATION
NEEDS AT
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LINK:

WWW.KENTALIS.NL

(IN DUTCH)



Royal Kentalis is a national organization in the Netherlands, specialized in providing diagnostics, care and education amongst others to the individuals who are deafblind. Our expertise is focused on bridging communication barriers.

Our staff members work in order to support children and adults who are deafblind but also individuals having hearing loss and / or complex communication needs. Important themes are access

Kentalis Academy

At the Kentalis Academy over 50 scientists conduct research together with healthcare professionals, educational professionals and experts (individuals who are deafblind, parents). We collaborate (inter)nationally with other healthcare, education and knowledge institutions. Our research is focused on improving the quality and effectiveness of our healthcare and educational services.

About 15–20 researchers work on the Deafblindness and Complex Communication Needs research program. We share our knowledge and latest insights with people from our target groups, their environment and with professionals.

Deafblind International (Dbi)

Kentalis was one of the founders of Deafblind International in the 1950s. We have been a large corporate member of Deafblind International since then. We find it

Contact

Trees van Nunen, Dbi Network Coordinator (0031612717768, t.vannunen@kentalis.nl) and

to communication, information, daily living skills and awareness. Kentalis offers care (assessment, therapy, adapted living, day care and work), schools for the deafblind and research.

For example, by developing and organizing professional training.

Deafblindness and Complex Communication Needs chair

Saskia Damen has been appointed professor by special appointment at the University of Groningen (RUG) on September 1, 2022.

In the chair of Development and Learning of Persons with Multiple Disabilities and Complex Communication Needs and of Persons with Congenital or Early Acquired Deafblindness she focuses on the development, evaluation, and implementation of diagnostic tools and interventions.

very important to organize knowledge and find connections all over the world as the number of the individuals who are deafblind is very small.

Esther van Dijk, Dbi Treasurer (0031621897031, es.vandijk@kentalis.nl).

Deafblind Ontario Services (Canada)

Deafblind Ontario Services provide an array of services to the individuals having hearing loss, hearing impairments, speech disorders and to the individuals who are deafblind that are customized to each individual's unique needs, method of communication, and goals to enrich their life.

LINK:

[HTTPS://
DEAFBLIND
ONTARIO.COM/](https://deafblindontario.com/)

VIDEO:

[HTTPS://YOUTU.BE/
GEEHPXWDZLW](https://youtu.be/GEEHPXWDZLW)



Roxanna Spruyt, Chief Executive Officer (CEO)

Their team of professionals is dedicated to ensure that the consistent person-oriented plans are in place for each person supported. Led by the wishes of each person supported, their individualized and holistic approach creates connection, belonging, and enriching experiences.

Deafblind Ontario Services believes in endless possibilities. These possibilities begin with

excellence in the field of deafblindness. A new certification, Certified Deafblind Intervenor Specialists (CDBIS), encompasses several years of work from CNIB Deafblind Community Services, Deafblind Ontario Services, and the Academy for Certification of Vision Rehabilitation (ACVREP).

CDBIS are highly skilled in providing auditory, visual, and tactile information to someone with



■ LARGE CORPORATE MEMBERS

dual sensory loss. Certified professionals demonstrate quality care, knowledge, and ethical practice in their field. This establishes credibility and a high level of trust to employers, as well as people that receive services from the CDBIS. Certification is open to any intervenor that meets eligibility and passes the certification exam. Learn more at <https://www.acvrep.org/certifications/cdbis-landing>

Endless possibilities are also inspired by Deafblind Ontario Services value of being a leader. Earlier this year, the organization's Chief Executive Officer (CEO), Roxanna Spruyt, was awarded with Deafblind International's (Dbi) Distinguished Service Award. This achievement was announced at the 2022 African Conference and recognizes people who have significantly contributed to the deafblind field or Dbi internationally.

One of the ways that Roxanna contributes significantly to Dbi is through the role of Communication Ambassadors Coordinator, as part of her role at the Communication Committee (ComCom). With Roxanna and ComCom's leadership, Ambassadors around the world help Dbi to be the point of connection in deafblindness by leveraging their knowledge and expertise in communications to drive awareness about deafblindness, quality services, and Dbi.

Deafblind Ontario Services is proud to be a Dbi Large Corporate Member since 2012, and a Small Corporate member in 2003–2012. Membership has connected the organization with individuals and organizations in the field worldwide, and supported Deafblind Ontario Services in constantly evolving and striving for excellence in everything they do. Learn more at <https://deafblindontario.com/>

ONCE and its Dbl Commitment

The ONCE Social Group is made up of ONCE, a service provider for the individuals having vision loss, ONCE Foundation, an organization that promotes employment, training and accessibility, and ILUNION, its company service group. All three together employ more than 71,000 workers, 58% of which are people with disabilities.

ONCE, the Spanish National Organization of the Blind, is a self-funded, not-for-profit organization. It is the only organization of the individuals having vision loss or who are visually impaired in Spain. There are around 72,000 members.

Its main mission, since it was created 8 decades ago, is the inclusion of the individuals having vision loss, people with severe vision impairment and the individuals who are deafblind, by offering them the opportunity to get a decent job and full self-reliance. This is achieved through a wide range of specialized services and a team of 1,500 professionals, psychologists, occupational therapists, teachers, bibliographic technicians, etc., who serve them.

More than 3,200 members of ONCE, around the 4.5% of the total membership, live with deafblindness. Taking into account their specific characteristics and needs, ONCE considers them a preferential care group and provides them with specialized services and specific programs, such

as: education, intervention in the area of communication, rehabilitation, instruction in the use of technical aids, information and communication technologies, adjustment to disability, speech therapy, among others.

In addition, FOAPS, the ONCE Foundation for the Attention to People with Deafblindness, provides its service to the individuals who are deafblind and need the support of an intervenor.

The principles on which ONCE is based: solidarity, general interest, equality, and full participation, are values that we share with Dbl.

That is why ONCE has been a member of Dbl since 1982 and in 1997 we had the honor of organizing the IV European Conference of Dbl in Madrid, Spain.

We firmly believe that networking, the exchange of experiences, knowledge and professional practices at an international level will help us achieve better services that result in a better quality of life for the individuals who are deafblind.

LINK:
[HTTPS://WWW.ONCE.ES/](https://www.once.es/)

VIDEO:
[HTTPS://YOUTU.BE/9GHKUJKWDSO](https://youtu.be/9GHKUJKWDSO)



Sensity

D.F. MCCOURT

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LEARN MORE
ABOUT THE
SUPPORTS
AVAILABLE TO
ONTARIANS WHO
ARE DEAFBLIND AT
[SENSITY.CA](https://www.sensity.ca)

VIDEO:
[HTTPS://YOUTU.
BE/9_B7EWWVEOE](https://youtu.be/9B7EWWVEOE)



Sensity is a registered charity providing intervenor services, programs and other supports to the individuals who are deafblind. Our non-profit organization is recognized in Canada and around the world as a leader in the provision of intervenor services.



Opening the World to Ontarians with Deafblindness

Interview with Cathy Proll, CEO, Sensity – Deafblind and Sensory Support Network of Canada

Deafblindness comes in many shapes and forms. Some people are born with dual sensory loss, while others come to it later in life. For all Canadians who are deafblind, however, access to intervenor services is the key to independence.

Independence is health. The ability to forge our own paths and the empowerment to direct our own lives is precious and too often taken for granted until it's threatened by illness or disability. For the Canadians who are deafblind – those with varying degrees of

dual sensory loss encompassing both hearing and vision – nearly every aspect of the way our world is built represents a challenge to their independence. So the tools which can help win that independence back are valued above all else.

The most effective intervention to empower the individuals who are deafblind is through the use of an intervenor, a specially-trained professional who is able to assist in communication and other tasks. “In layman’s terms, intervenors become the eyes and the ears of someone who is deafblind,” explains Cathy Proll, CEO of Sensity – Deafblind and Sensory Support Network of Canada. “Compared to, say, an ASL interpreter, who is typically only interpreting language, an intervenor will be interpreting the entire environment. It’s a unique role that intervenors play in bridging that gap and supporting the individuals who are deafblind.”

“It can be very isolating. But, with an intervenor, the possibilities are endless.”

From “everything is impossible” to “anything is possible”

With the proper support, the degree of independence an individual who is deafblind can achieve has no limit. Without proper support, however, the limits of life can shrink to a claustrophobic degree. “Deafblindness affects so many things beyond simply communication,” says Proll.

It affects your mobility and broadens the gap between you and the world around you. It can be very isolating. But, with an intervenor, the possibilities are endless. One gentleman we support has obtained his first teaching degree and now his law degree. We have people who engage in all kinds of recreational activities, from travel to whitewater rafting. When someone has access to an intervenor, it’s up to them to decide how they want to use those services.

In addition to providing intervenor services for children and adults across Ontario, Sensity also provides advocacy and training to ensure that the needs of the deafblind community are being met. Unfortunately, good intervenors, proficient in skills like two

hand manual communication – a highly specialized touch-based sign language – can be difficult to find. As a result, it’s a continuous effort to recruit new professionals into this demanding but rewarding field, especially in more remote and rural communities.

“I have to give kudos to the Ministry of Children, Community and Social Services because they’ve been incredibly supportive, and they’ve built a great system,” says Proll. “I don’t know of anyone who wants intervenor services right now that’s going entirely without.”

Doing right by our most vulnerable

However, there remains a persistent gap in the services available to children at greater risk of developmental delay when their deafblindness is inadequately supported. “Students often aren’t getting the services that they require, and there’s absolutely nothing outside of the school setting for students who are identified specifically as deafblind,” says Proll. “Ontario is the opposite of the rest of the world in that way because, in most places, services for children are in abundance and services for adults are very scarce.”

In pursuit of equity and self-determination for all the individuals who are deafblind in Ontario, better access to intervenor services for children and rural citizens represent challenges. But the biggest challenge of all is perhaps simply awareness. So many Ontarians live with sensory loss without knowledge of the services and supports that are available to them. More than anything else, Proll wants the individuals who are deafblind to know that independence is within reach. Intervenor services are available, and they can reopen the doors to the world.

Learn more about the supports available to Ontarians who are deafblind at sensity.ca

https://youtu.be/9_b7EwWveOE

An Analysis of Factors That Promote Transition of Learners with Deafblindness to Independent Living

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Abstract

Preparedness of learners who are deafblind for transition to independent living has been a major concern in Kenya. The government is investing heavily in education, but there is however limited research on this topic. The purpose of this study therefore was to establish the extent of preparedness of the learners who are deafblind for transition to independent living. The objectives of the study were to establish the following: the extent of early identification and intervention of deafblindness; the role of parents in whole upbringing of a child who is deafblind; the extent to which learners who are deafblind have acquired necessary skills for transition to independent living; and the general provisions in promoting acquisition of skills necessary for independent living of the learners who are deafblind. Findings of this study have indicated a disparity between the age of identification

and admission to school. Majority (31, 94.0%) of the learners were identified at the age of below 4 years but were admitted to school after 6 years of age indicating late intervention. Reports by most teachers (22, 88.0%) indicated that the role of parents was mainly utility-based with minimal engagement in their children's learning process. The vocational skills (average of 1.89) and literacy skills (average of 1.63) turned out to be the least acquired by the learners who are deafblind, the extent of these skills acquisition was found to be minimal. Basic provisions for the learners who are deafblind were reported to be available with limitations in the terms related to policy, curriculum differentiation, expectations on learners, teacher motivation, and parental involvement.

Key words: deafblindness, early intervention, transition and Independent living

Introduction

Agenda 2030 and the sustainable development goals emphasize the importance of leaving no one behind and ensuring quality and

equity in education. Consequently, learners with deafblindness have a right to quality education that promotes independent living from

early childhood to adulthood. All learners in Kenya are expected to transit from primary to secondary education. However, reports indicate that transition from primary to secondary school, from vocational studies to job placement remained a major challenge, especially for learners with severe disabilities (Special Needs Education Policy Review Data Collection Report, 2016). According to Ochieng, 2019, the learners with severe, profound and multiple disabilities experience challenges in transition compared to those without and with mild and moderate disabilities.

Early identification for learners with disabilities is still a challenge in Africa as seeking help is the last thing most parents do (African Union of the Blind, 2007). Children with severe developmental disorders are often not brought for assessment because the parents have lost hope and some prefer just to hide a child in the house (Marphatia, Edge, Legault & Archer, 2010). In Kenya, Educational Assessment and Resource Centers (EARCs) have been set up for early identification, assessment, intervention and placement of children with special healthcare needs including those who are deafblind (Bii & Taylor, 2013). The extent to which the EARCs have promoted early identification and intervention of the learners who are deafblind is however unknown.

The role of parents or guardians of ensuring that children with special healthcare needs access education is clearly spelt out in the

Methodology

The descriptive survey research design was adopted for this study. The study was carried out in 1 school and the units for the deafblind in Kenya located in Baringo, Kisumu and Nairobi counties. Study population comprised 38 learners who are deafblind and 35 teachers. Saturated sampling technique was used to select 33 learners who are deafblind and 25 teachers.

Research instruments included questionnaire for teachers and interview schedule for parents. Face and content validity of the research instruments was established

Basic Education Act (Republic of Kenya, 2010). Specifically, parents have a key role in ensuring curriculum implementation, ensuring fulfilment of basic necessities, engaging with the teacher to enrich the child's learning experiences, monitoring the child's growth and development, and identifying any signs of disability for early intervention (Republic of Kenya, 2016).

Sector Policy for Learners and Trainees with Disabilities (Ministry of Education, 2018) further recognizes provisions for the individuals with disabilities including as follows: assessment and early intervention, access to quality and relevant education and training, quality learning environment, health and safety, barrier-free environments, and specialized learning resources. This provides a basis of the necessary provisions that should be in place in educating learners with deafblindness.

Before transition, a learner who is deafblind is expected to have acquired numeracy and literacy skills, orientation and mobility skills, adaptive skills for living, social skills, communication skills, positive attitude towards the world of work, physical fitness and personal talents, and vocational skills that will enable them to participate in income generating activities (Kenya Institute of Curriculum Development, 2013). The research on the extent to which the learners have acquired these skills in preparation for transition to independent living is however still minimal. Hence, there is the need for this study.

through expert opinion. Reliability of the research instruments in this study had been established through a pilot study involving 10 teachers and 5 learners who did not take part in the actual study.

Quantitative data was analysed using means, frequency counts and percentages. Qualitative data was analysed, organised and reported according to emerging themes. A rating scale was used in establishing the extent to which the learners who are deafblind had acquired necessary skills for transition. The score values were assigned as follows:

Very Large Extent (VLE) = 5 points, Large Extent (LE) = 4 points, Small Extent (SE) = 3 points, Very Small Extent (VST) = 2 points and Not Yet Acquired (NA) = 1 point. Skill

acquisition average score of 2.99 and below was interpreted as very small extent, between 3.0 and 3.99 as small extent and 4 and above as large extent.

Results and discussion

Extent of early identification and intervention for learners with deafblindness

The study established that there was disparity in terms of age of identification and admission to school with most learners joining school at the age over six years. This has implications on the overall development of the child with a likelihood of lagging behind in cognitive development and other

developmental milestones. The disparity can be associated with the social-economic status of the parent where most were found to be farmers (22, 66.7%) and stigma. Early intervention ameliorates the impact of disability on a child in terms of early acquisition of skills and developmental milestones.

General provisions in promoting acquisition of skills necessary for independent living of learners with deafblindness

Reports from 19 (76.0%) of the interviewed teachers indicated availability of the general provisions for acquisition of skills necessary for independent living of the learners who are deafblind in respective schools. The provisions included learning materials and facilities, support from government and well-wishers, and human resources. This is evidenced by the following response:

Teacher 15, "We have facilities in terms of classroom space, teaching and learning resources that are used to facilitate learning of various skills in various learning areas of the curriculum design to equip the learner with the necessary knowledge, skills and attitude".

Teachers (20, 80.0%) however reported challenges related to the general provisions including inadequate resources, payment of school fees and provision of basic necessities

by parents, involvement of parents in reinforcing acquired skills, learners taking too long to acquire skills, lack of consistency due to learners' non-attendance, curriculum limitations in terms of relevant skills for the learners who are deafblind. This is evidenced by the following responses:

Teacher 3, "It takes so many years for the children to learn skills and some of the children do not even acquire the skills desired".

Teacher 9, "The curriculum has been amalgamated with some other severe cases of disabilities and does not support the unique needs of these categories of learners to a great extent".

Teacher 11, "Where there is no formal assessment of learners, there tends to be negligence and underexpectation of learners' acquisition of skills, which is especially common for parents".

Role of parents in promoting transition of learners who are deafblind to independent living

Majority of the teachers (22, 88.0%) reported that the roles of parents in their school included provision of basic needs to the learner, providing information regarding their children and paying school fees. Collaboration with the school in enhancing skill development of learners who are deafblind was only

mentioned by 1 teacher (4.0%). This indicated that most teachers perceived the role of parents as material provision with minimal expectation in terms of participation in their children's learning process. This was further supported by 19 (76.0%) of the teachers who indicated that the extent of parental

participation in the learning of children who are deafblind was minimal.

On the other hand, parents reported their roles as payment of school fees, shopping and transport. This is evidenced by responses from parents 2 and 8:

Parent 2, "I do my work as a parent by paying school fees, going shopping for basics and fulfilling essential needs at home".

Parent 8, "I pay school fees and do shopping for my child. At home I ensure that my child

eats well. You know, these special children need special diet".

Provision of basic necessities is one among many of the roles of parents stipulated by the Kenya Institute of Curriculum Development (2016). Evidence from this study however indicates that the role of the parents in terms of engagement in the learning process is yet to be acknowledged by parents of the learners who are deafblind. Minimal engagement of parents in the learning process of the learners who are deafblind therefore implies limited skill acquisition which negatively affects their transition to independent living.

Extent of acquisition skills of necessary for transition to independent living

The skills considered for the study included daily living skills, orientation and mobility skills, communication skills, literacy skills,

vocational and social skills. Results are represented in Table 1.

Table 1: Extent of Acquisition of Skills Necessary for Transition to Independent Living (n=25)

Skill	Average	Standard Deviation
Daily Living Skills	2.73	0.93
Orientation and Mobility Skills	3.30	0.94
Communication Skills	2.76	0.87
Literacy Skills	1.63	0.74
Vocational skills	1.89	0.91
Social skills	2.64	1.03

According to Table 1, the extent of orientation and mobility skills acquisition was small (Average=3.30, SD=0.94). The skills that had been acquired to a very small extent included daily living skills (Average=2.73, SD=0.93), communication skills (Average= 2.76, SD=0.87) and social skills (Average= 2.64, SD=1.03). The skills that haven't been acquired yet included vocational skills (Average=1.89) and literacy skills (Average= 1.63, 0.74). It can therefore be deduced that extent of skill acquisition among the learners who are deafblind is minimal.

The ability of the learners having hearing loss to fairly move from one place can be

attributed to the frequency within which the learners move from one place to another in performing daily activities. However, the extent of acquisition would be considered as inadequate to enable a learner who is deafblind to function independently. This implies that upon transition a learner who is deafblind may not be aware of where they are or where they want to go. In addition, they will experience challenges in moving safely, efficiently, and effectively within their environment.

The low level of vocational skills acquisition limits the opportunities for the learners who are deafblind upon transition in terms

of further skill development, job opportunities, independence in life and becoming productive members in the society. Low literacy skills on the other hand hinder the learners who are deafblind from communication,

access to information, entertainment, financial negotiations, identifying things and places which ultimately results in dependence and inclusion in the society.

Conclusion and recommendations

The study reveals that the acquisition of necessary skills for transition of the learners who are deafblind in Kenya was minimal hence the learners were not adequately prepared for transition to independent living. The study therefore recommends: (1) Involvement of teachers of the learners who are deafblind in curriculum designing

(2) Empowering parents in supporting their children's education and eventual transition (3) Strengthening policies related to early identification and transition of learners who are deafblind (4) Provision of quality human and material resources by the government for effective skill acquisition by learners who are deafblind.

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Ecological Assessment and Individuals who are Deafblind

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This is the 7th article in a series addressing the assessment of children and adults who are deafblind. In special education, ecological assessments examine the relation between the individual's performance and the physical and social characteristics of the environment. Ecological inventories, ecological analysis, and task analysis are closely related ecological assessment methods discussed in this article.

Ecological Inventories

Ecological inventories are conducted for different purposes and may occur at school, home, or other environments. A community ecological inventory may be used to identify the environments in which an individual who is deafblind currently participates, as well as potential instructional environments. Each environment includes sub-environments within which activities occur. For example, the environment of the school may include sub-environments such as the general education classroom, the special education classroom, the luncheon, the bathroom, hallway spaces, and more. One could also define the classroom as the environment and then areas of the classroom as sub-environments. The activities that occur in each sub-environment place different demands on an individual who is deafblind. When conducting a home ecological inventory, parents will give input to identifying

sub-environments and typical family activities that occur in each of them (Mohsin, 2011). The skills required by an activity can then be analyzed to determine which of the skills an individual who is deafblind already demonstrates and at what level of independence, as well as the appropriate assistive technologies to support active participation. The teachers apply culturally sustaining practices by honoring the family's culture and associated daily practices, and by teaching skills that will improve the child's participation in valued home activities.

Ecological inventories can be helpful to planning communication interventions. A sub-environment may be analyzed to determine the activities that occur there and the communicative messages and intents most often expressed. The educational team may consider which of those messages

an individual who is deafblind currently expresses and which would be worthwhile to teach. For example, if an individual who is deafblind regularly uses the city bus with a family member, what communicative messages could be taught that would increase

Ecological analysis

Ecological analyses may be used to examine the impact of each environment, sub-environment, and activity on behaviors that are perceived by others to be positive or negative.

This includes communicative behaviors that may be environment specific. This analysis is crucial for individuals who are deafblind and prelinguistic or early linguistic communicators because a complete environmental analysis can support others to identify and respond to their subtle communicative behaviors. Thus, ecological analysis provides contextual information that can support others to better understand the communicative behaviors of an individual, as shaped by the physical and social characteristics of the environment. Additionally, ecological analyses are useful for identification of accelerator behaviors which are related to supporting a learner's progress toward a goal and the factors in the environment which facilitate accelerator behaviors (Carta et al., 1990). These environmental factors may include natural cues that motivate a learner to initiate a goal-directed behavior, as well as directions, cues, and responses provided by others.

Ecological analysis can be also used to identify activity-specific learner behaviors that interfere with participation and negatively impact behavior. An analysis of the environment may identify characteristics that are distracting or upsetting an individual, such as noise, visual clutter, or closely spaced seating. This type of ecological analysis can

Task analysis

A task analysis is a written document that defines and sequences each of the steps to be performed within an activity. Task analyses are customized to each individual,

the individual's participation? When selecting target instructional vocabulary, the team may consider the generalizability of the new communicative message across activities and environments.

then be paired with the Functional Behavior Assessment (FBA) to identify what happens before, during, and after the negative behavior (Venn, 2014), as well as to determine the primary function of the behavior, such as seeking attention or escape. Parents and professionals may then apply this information to make changes in the environment or to teach coping strategies to an individual who is deafblind.

Comprehensive ecological analysis will require meticulous classroom observations with learner behaviors coded within time blocks (DeSouza & Sivewright, 1993). The behaviors are then coded according to the purpose of the ecological analysis, e.g., to identify communicative behaviors, goal-oriented behaviors, or behaviors that interfere with goal attainment or participation in the activity. By replicating this process across environments, it is possible to develop a comprehensive understanding of the different environments in an individual's life and how these environments and their behavior interact.

Given that ecological analysis provides meaningful information regarding not only the physical factors but also the social and behavioral factors at work in an environment it is a crucial precursor to an effective task analysis (Szidon & Franzone, 2009). For example, ecological analysis may identify natural reinforcers within an activity, thus influencing decisions about prompting and reinforcement that may be included in a task analysis.

considering the learner's age and what is developmentally appropriate (Szidon & Franzone, 2009). This could include addressing communication methods that will be

used during the task or outlining any necessary accommodations which an individual may need. It may also describe the level of prompting needed for each step of the task. The task analysis can then be used to record the learner's performance of the task over time. Thus, task analyses are powerful when used in progress monitoring because they

are a curriculum-based measure that informs the team about how the learner is performing a task that is regularly instructed. The following resource explains how to create a task analysis for daily living skills and shares an example that includes levels of prompting (Dees, 2022): <https://www.n2y.com/blog/teach-life-skills-with-task-analysis/>

Conclusion

Community ecological inventories are crucial for the identification of environments in which an individual who is deafblind currently participates, as well as of potential environments for future participation. An ecological inventory of a specific environment will support the identification of activities and

provide the assistance required to ensure engagement of the individual. When combined, ecological analysis and task analysis are helpful to examine the interaction between environmental demands and the unique strengths and needs of each learner who is deafblind.

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The Importance of “Yes” and “No” for Students with Visual Impairment and Additional Disabilities

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Introduction

Children with visual impairment and additional disabilities are part of a heterogeneous group where visual impairment is the common feature. Additional disabilities can range from intellectual disability, physical disability, cerebral palsy, pervasive developmental disorders, learning disabilities, medically fragile conditions to complex communication needs (Chen, 1995).

Complex communication needs prevent the use of communication skills to satisfactorily meet all of the child's needs. In some cases, this is temporary and in others it is permanent.

Goldbart and Caton (2010) mention that the communication of these children is described as pre-verbal, as they express themselves through elementary modalities used before words and formal language, in an idiosyncratic way. Complex communication needs are experienced differently by each child. Some cannot speak, but use gestures to communicate, others can speak single words in specific contexts, but still do not form simple sentences. And there are those who have very confused speech.

Communication is an essential basic right of all human beings. Through communication it is possible to express needs, interests and feelings, likes and dislikes, interact with other people, participate in the community and make decisions (Goldbart & Caton, 2010). Therefore, encouraging children to answer basic questions about daily situations reliably through verbalizations, vocalizations, natural gestures or with tactile resources of alternative communication, represents an important goal to be achieved in the lives of children with visual impairment and additional disabilities (Lancione et al., 2006).

According to Moreira (2021), the tactile resources of communication include reference objects, tangible symbols, tactile symbols, and textured symbols. This work highlights the value of reference objects in favouring communication and understanding of simple everyday requests.

Reference objects are those that receive special meanings associated with them (Ockelford, 1993). They can represent different concepts for the same purposes as a symbol, in the same way as the

spoken, written or signed (Ockelford, 2002). A partially literate child can appropriate the linguistic code “ball pit”. While a child having vision loss can appropriate this term in the Braille version. A child who cannot read or write may pick up a plastic ball from the ball pit to express interest (Ockelford, 1993; 2002).

Ockelford (1993) grouped reference objects into five categories. The 1st category refers to activities where a certain item is used in a certain activity. For example, the action of drinking can be represented by a small glass. The 2nd category involves time which is a very abstract concept as far as children’s understanding is concerned. A wristwatch or wall clock can represent this concept. The 3rd category includes the qualifiers that are represented by the concepts of “Yes” and “No”, beginning and ending. The 4th category corresponds to places that can be represented by objects that allude to the place they represent. The 5th category refers to

the people. The used objects must relate to specific people.

Considering the aspects highlighted above, this work aims to present a key chain with objects of reference and the concrete symbols of “Yes” and “No” to favor the expression of the opinion of young people and children with visual impairment and additional disabilities regarding situations of their daily lives. In addition, it is expected to encourage choices between activities of interest and understanding the meaning of objects associated with daily actions.

The keyring was made with low cost materials. The cards in this reference object key-chain can represent part of a child’s or young person’s routine. The concrete symbols of “Yes” and “No” serve to value the opinion of the young person or child in relation to what they like and don’t like or what they want or don’t want. Images of these materials can be found below.

Figure 1. Communication and routine keyring. Source: Prepared by the author



Figure 2. Communication cards forming a sequence of routine activities.
Source: Prepared by the author



Figure 3. Concrete symbols of “Yes” and “No”. Source: Prepared by the author



To properly understand the information offered by the cards shown in the previous images, active touching plays a significant part in coding and recognizing reference objects and associating them with their meanings. In this case and in many others, touching plays an essential role in structuring the mental representations of the body and the disposition of our limbs in relation to ourselves and the surrounding environment (Bremner & Spence, 2017). The way in which the brain attributes self-ownership to the space that the body occupies favours the special tactile representation building the perception of the sense of self.

Considering the importance of touch, children and young individuals having visual

impairment and additional disabilities and complex communication needs require opportunities to use, in a contextualized way, “Yes” and “No” responses in relation to preferred and non-preferred events and stimuli (Lancione et al., 2006).

This work has great relevance, so disseminating it among teachers, professionals and family members is of paramount importance to enhance communication and strengths of children and young individuals who communicate through informal and idiosyncratic modalities. When they fail to understand and properly use “Yes” and “No” answers, direct questions and choices become very limited.

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Meeting Problem of Lack of Independence in Communication and Services Accessibility with HaptiBraille



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Figure 1. A picture of the device

About company

4Blind conducts research, designs and produces innovative engineering solutions. We help in meeting needs of the communities of the individuals who have vision loss and who are deafblind by expanding their opportunities and eliminating the barriers

that people with disabilities face in communication, education, employment and independent living. Our mission is to improve the well-being of the individuals who have vision loss and hearing loss through innovative technologies.

Problem

A trigger to begin our activity in this direction was the unfair fact that the individuals who are deafblind have limited abilities for such a basic thing as communication and interaction with people around. We also pay significant attention to the issue of absence of independence and low accessibility of services for the individuals having simultaneous vision loss, hearing loss and speech disorders.

We focused on solving these problems and began our work. We have been doing research for 4 years with the aim to create an affordable technology that will make it easy for an individual who is deafblind to communicate independently with any person at any time.

Technology

The result of our research and engineering developments is the world's first communicator that allows an individual who is deafblind to speak in a synthesized voice and hear the speech of the interlocutor.

The performance of the device functions is carried out through receiving and transmitting information according to the Braille alphabet principle.

The words of a user who is deafblind are transmitted by pressing 6 main keys on the front panel, which are located as the Braille dots. The received signals are converted into text and voiced to the interlocutor.

Spoken words of the interlocutor are converted into tactilely vibrating signals and transmitted to a user who is deafblind through the same main six keys. The user

Users

The principle that underlies the operation of the communicator allows it to be used by various categories of users. Thus, it can be used by people with speech impairment due to stroke or aphasia. In addition, among the users of the device there are people with low sensory level of fingers, since they can



Figure 2. HaptiBraille communicator in use

reads words tactilely by placing their fingers on these keys.

Heart of the device is Google technologies. Thus, the reception of speech of the interlocutor for further transcoding of the voice information into silent tactile signals is carried out through the Google speech recognition function. In turn, the user's response entered in Braille is voiced to the interlocutor due to the function of the speech synthesizer.

Working with Google, we also see that we can empower individuals who are deafblind not only by using speech recognition and synthesis technology, but also by using the translator function. Thus, we can break another language barrier in communication. In the future, we will release a feature allowing a user who is deafblind to easily communicate with a foreigner by simply changing the language of communication in the mobile application.

communicate without having to tactilely recognize the Braille dots, but only knowing principle. Also, among the current users there are people having hearing loss, who find it difficult to communicate using a hearing aid at home and prefer to use the HaptiBraille Communicator.

Testing and pilots

We have been conducting testing and pilots of the HaptiBraille for years in a number of the largest specialized organizations in different countries, among which are Helen Keller National Center for Deaf-Blind Youths & Adults (New-York, USA), LightHouse for the Blind and Visually Impaired (San Francisco, USA), Massachusetts Commission for the Blind (Boston, USA), National Braille Press (Boston, USA), Ire-AT Vision Aids for Macular Degeneration (USA), School Health Health Supplies (Illinois, USA), etc.

During pilot programs we have assessed the effectiveness of the device and identified characteristics requiring improvement. The technology received recommendations from

various organizations stating that it greatly contributes to the empowerment of the individuals who are deafblind, greater level of independence and their integration into society.

Conducting tests showed the following results, in which three key indicators can be distinguished:

- On average, it takes a user 1–2 minutes to learn how to use the device, if they know Braille;
- On average, the user can type 35 words per minute;
- The average speech comprehension is 46 words per minute.



Figure 3. The process of using HaptiBraille communicator

Usage and affect

We have already released the device and started training programs. Today, more than 50 people use the device. Observing feedback on the device usage in everyday life, we can say that its use will lead to the significant changes.

By breaking down barriers in communication, the device contributes to making various organizations and public places much more accessible, since the staff will be able to interact directly with those who have vision loss, hearing loss and speech disorders.

This fact will lead to the increase of social activity of the individuals who are deafblind.

The individuals who are deafblind gain more privacy when it comes to a discussion of sensitive matters with doctor, lawyer, bank

manager where they needed to have an accompanying assistance before.

Moreover, the HaptiBraille provides the individuals who are deafblind with broader opportunities for education and realization of their potential in professional development.

Conclusion

We believe that this solution will make a contribution to the development of society with equal opportunities. Even though the device is very simple, it is can be a life changing solution which will significantly extend the level of independence for many individuals who are totally deafblind.

In conclusion, we would like to thank all those people and organizations supporting the individuals who are deafblind and of course, to say many thanks to organizations that tested our technology, conducted pilots and gave recommendations, for their valuable time and contribution to our work.



INTERVIEW BY
ROYAL KENTALIS

[HTTPS://WWW.
KENTALIS.NL](https://www.kentalis.nl)

Senior researcher Saskia Damen (49) of the Kentalis Academy has got another great appointment in addition to her position at Kentalis as of 1 September 2022. As of that date, she is also Endowed Professor in Complex Communication Needs and Deafblindness at the University of Groningen in the Netherlands. The chair is entitled as follows: Development and Learning of Persons with Multiple Disabilities and Complex Communication Needs and of Persons with Congenital or Early Acquired Deafblindness. Kentalis is sponsoring this 5-year chair. Through the collaboration, Kentalis and the University of Groningen make use of each other's specific expertise to continue developing the most effective treatment methods for clients, parents/carers, teachers and practitioners.

Saskia was eager to get started and tells more about her mission, what drives her in the chair in particular and where she wants to be in 5 years.

Why did you choose this particular topic within the chair?

I would like to emphasise that the chair was installed by Kentalis, together with the Department of Pedagogical Sciences and Educational Sciences of the University of Groningen. We chose this topic because development and learning are major challenges for the individuals having CCN or for those who are deafblind. People with CCN have two or more disorders, which together cause severe barriers to communication. Deafblindness involves an impairment in both hearing and vision. In both target groups, the picture is more complex than the sum of its parts. The interaction between the separate disorders leads to very specific support needs in communication and language acquisition. It is also a major challenge for parents, caregivers and teachers to support these individuals in their development and learning. They need specific knowledge and skills to do so. And that's where the results of this study are definitely going to help them with.

What is your personal mission in the chair?

I see the people themselves as my driving force. So my mission is to ensure that together with the individuals having CCN and with those who are deafblind, with their parents and professionals, we bring effective methods to life, to properly map and promote development and learning in the individuals having CCN or in those who are deafblind. Moreover, these methods are actually applied practically. Not only during childhood and adolescence, but throughout a person's life span. What I also think is important, is to realise that the learning doesn't actually take place only at school, but rather outside it: in everyday life and in contact with others, such as peers. The learning doesn't stop after the school age. Besides, what I sometimes notice is that parents cannot always communicate at the same level as teachers and support workers. Therefore, I strive for much more attention for the important

role parents and family members can have in fostering communication and other developmental and learning domains of an individual having CCN or an individual who is deafblind. They are the continuous factors in that person's life. Therefore, we need to support them much more and also involve them a lot in research.

Where will we be in five years when it comes to this topic?

Firstly, by then, there will have been more awareness about CCN and deafblindness and about the opportunities that are already there to support people with these conditions in communication, learning and overall development. In addition, what we have developed for the home-situation, for care and educational settings in recent years will then be implemented. We will also have an even better understanding of what the practice really needs, so that we can continue to give adequate treatment and support. Moreover, parents, family members, and other educators will then be better equipped and well-involved in the research.

How do you connect research with care and education within Kentalis?

By determining, setting up and implementing the research themes together with the individuals having CCN and with those who are deafblind, their families and people involved in their care and education. And of course by keeping these people well informed of developments within our research. The implementation of research results in practice and further development are also very important, so that the methods developed continue to match with what the target groups need. A good example is Thinking in Dialogue, PhD research conducted by Kim Tosolini. In this research, we developed a training for teachers, parents and supervisors in stimulating the cognitive development of the individuals with congenital deafblindness. The motivation was a comment made by a parent during a symposium on communication interventions. There, a parent asked why there was no training for parents in stimulating the cognitive skills of the children who are deafblind. So we developed such a

training and are now also testing how effective the training is.

What, from your point of view, are some other benefits of the cooperation between Kentalis and the University of Groningen?

Kentalis and the University of Groningen strengthen each other. There is a lot of knowledge within the university about how to conduct high-quality scientific research. There are several researchers who are highly specialised in a specific theme and in specific research methods. Within the academic context of the university, it is quite possible to combine this knowledge by working together. By collaborating with Kentalis, we ensure that what we do is not only a top-notch research, but that the research also connects well with practical problems and can have a lot of impact, because the results are also applied practically. I actually think that the best methods for diagnostics and intervention are always the result of good cooperation between people with live experience, professionals, and researchers.

Finally, what is currently your most important research at our Kentalis Academy and why is that research so important for our target groups?

Of course, there are several of them, but let me highlight one specifically. I think that the project Communication with Affective Technology – CAT for short – is very nice. It has been developed for the individuals having CCN and for those who are deafblind. In other words, a cuddle robot. Together with Emma Vaillant and Nina Wolters–Leermakers, I am trying to gain insight into the effects of a cuddle robot with these target groups. Much research has already been done with cuddle robots in people with dementia, but this is the first study in the target groups of CCN and deafblindness. The idea is that interacting with a cuddle robot could potentially be a nice activity during times when there is no interaction with a caregiver, for example because the caregiver has to help other residents. It would be great to be able to offer the individuals having CCN and those who are deafblind something at such moments, which can still be experienced as a form of contact. In our study, we are looking at the extent to which the individuals themselves will make contact and communicate with the cuddly cat. We will also consider whether it matters how a caregiver offers the cuddle robot to an individual: only with a short introduction or with a more extensive story about the cat.

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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.



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