

Deafblindness in Africa:

a Continent Sets Much Hope
on the 1st Dbi Africa
Conference

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DbI is **LOOKING** for **YOU!**

One of the main goals of DbI is to stay connected and of course we want all our communication channels to be accessible to people all over the world!

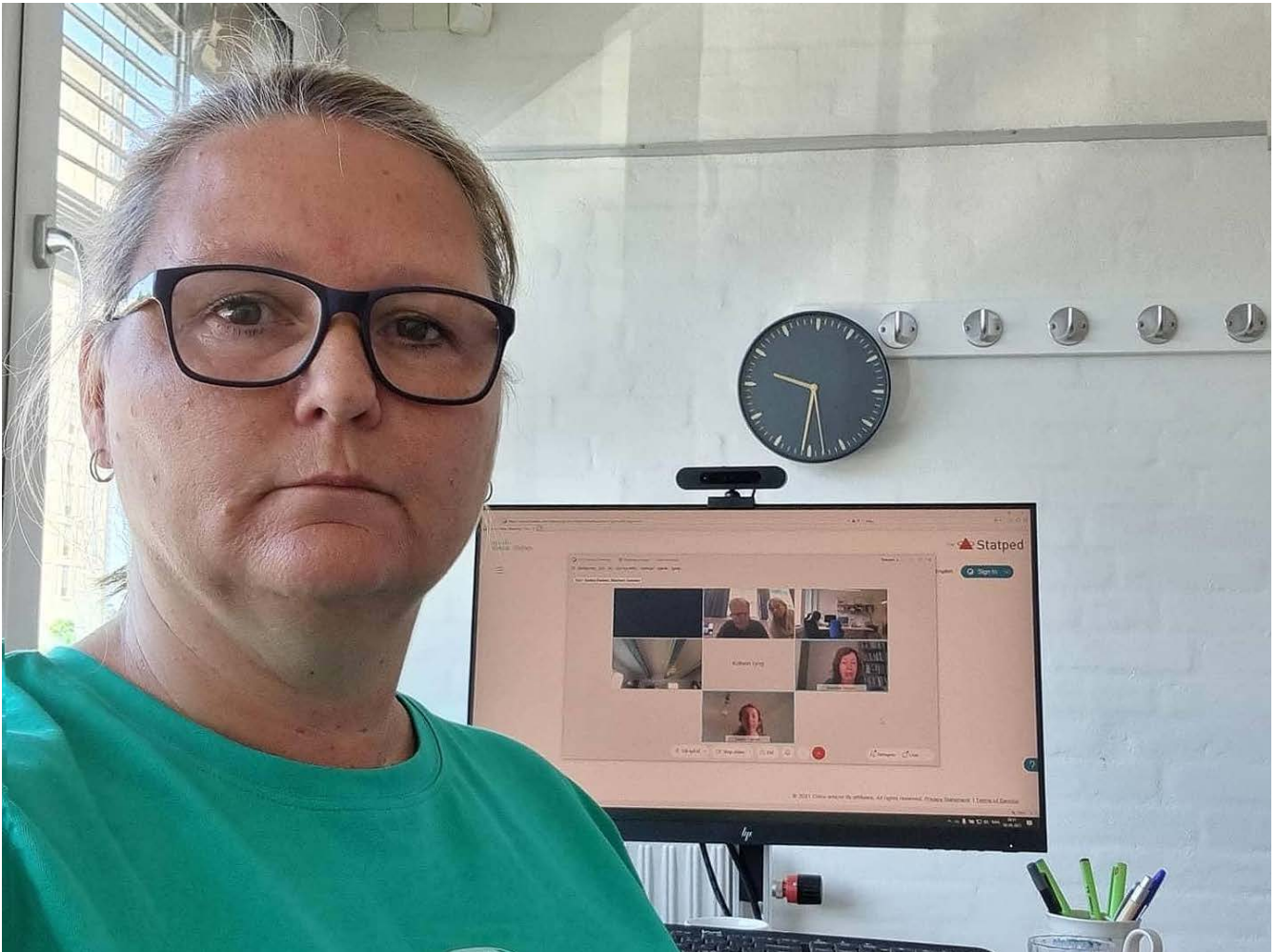
That's why we want to create

Website accessibility team.

And we are looking for persons with deafblindness all over the world who could review our websites accessibility.

If you are interested in this position, please email
academy@so-edinenie.org

We are looking forward for your answer



I'm often asked, why we focus on deafblindness as a unique disability? What makes it so unique? Many children and adults with rare disabilities or multiple disabilities could also benefit from our strong collaboration in the community of deafblindness, so why don't we exert all our effort to a broader area?

I've been a part of the working group around the Nordic definition of deafblindness (that, I know, is also used around the world) and my answer is the following: deafblindness is limiting the senses, that natural stimulus, natural interaction codes, natural environmental design are based on. Being able to see or hear, no matter what other disabilities we have, we learn most of all by watching and hearing what others do or talk about.

We get stimulated by what we see and hear in the environment. We get included by perceiving our connection to others and to the environment.

By focusing on the deafblindness and understanding how limiting it can be to have poor or no vision and hearing, we hereby focus on what particularities vision and hearing carry in our interactions with each other and with the society and how they do it. We do it because we need to understand these important particularities and translate them into tactile forms as support or as primary modality.

My assertion is that the knowledge of particularities would not have been acknowledged as important

**HENRIETTE
HERMANN
OLESEN**

VICE PRESIDENT
OF DBI

■ ADDRESS BY THE VICE PRESIDENT OF DBI

and would not have been half that detailed if we hadn't focused on deafblindness as a unique disability. The strong collaboration between organizations for individuals who are deafblind, WFDB and organizations around the world, that work with individuals who are deafblind is crucial. We need to stick together to accomplish things we have done today and things we can accomplish in the future. I am very happy that this collaboration is so strong and is getting stronger every day. I have been so honored to be invited to give lectures on this topic at two international conferences by Statped in Norway. And Dbl Communication Committee is working hard for this as well.

But of course, we would not have developed our knowledge without learning from the competences about hearing loss, vision loss, and communication. We need to work close with our sister-organizations ICEVI, WFD, ISAAC, WBU, IDDC to learn from each other. Therefore, we already have a memorandum with ICEVI, a membership in IDDC, a communication alliance with ISAAC, and we wish to

work on understanding with other organizations.

So, getting back to the original question, we need to keep focusing on deafblindness as a unique disability in collaboration with anyone in our own country, our regions and anyone in the world who is in contact with deafblindness. We cannot stand alone, and of course we cannot become better alone. Together with our close partners, we need to stay strong in vision loss, hearing loss and communication. We can learn so much from each other.

And getting back to the original question again, we should also exert our effort to a broader area. Our knowledge of small particularities in interaction, natural learning, and environment can be beneficial for many other groups with other disabilities. And therefore, it is important to share our knowledge with the others.

I will end my passage by sending all my thoughts to the invaded Ukraine. We will stand by to give any help we can, when needed.

All the best from Henriette Hermann Olesen, Vice President of Dbl.

Save the Date!

The 18th Deafblind International World Conference

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.



The 18th Deafblind International World Conference: Call for Abstracts



The Deafblind Network of Ontario (DBNO) will host the 18th Deafblind International World Conference in Ottawa, Ontario, Canada, from July 22 to July 28, 2023.

The theme of the event celebrates Global Connections: The Future in our Hands, which includes a comprehensive 4-day educational program.

For the first time, this conference will be designed as a hybrid event, offering content in-person and virtually.

All sessions will be recorded so that registered participants can view them after the event.

The Scientific Committee invites persons interested in presenting at the 18th Deafblind International World Conference to submit abstracts for presentations.

Presentations and abstracts that are created, designed, produced, implemented or analyzed with individuals who are deafblind are strongly encouraged.

The purposes of presentations are the following:

- To provide an opportunity for participants to present studies relevant to the field of deafblindness.
- To share practice innovations or program evaluations. Solution-focused and practice-orientated presentations are welcome.
- To present lived experiences that highlight unfulfilled needs in research, service provision, education or intervenor service.

The Scientific Committee welcomes submissions in forms of a traditional research abstract, workshop, lived-experience or presentation. The deadline for online submissions is **July 1, 2022**.

Please visit our website at: (deafblindnetworkontario.com) for more instructions and the [link to the submission portal](#).

If you have any questions, feel free to contact us at: dbiconference2023@dbno.ca.

News from the Network Coordinator

TREES VAN NUNEN

DBI NETWORK
COORDINATOR

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At the moment we have 14 networks and there is a 15th on the way: the Family Network! In the next Dbl Review, when the network is officially launched, we will tell you more about this wonderful initiative.

In the past period, great initiatives and activities have been taken from the various networks.

Based on the results of a survey undertaken among members, the Acquired Deafblindness Network (ADBN) has started a newsletter and the organization of short webinars every month. The Celebrating Your Everyday Contributions project is still a big success with contributions across the globe. Get inspired and take a look at the ADBN website.

The Youth Network released a new publication, called Cookbook, with recipes from around the world. You can find this recipe book on the Dbl website. Your mouth is watering when you are reading these various and delicious recipes! In addition, because of ongoing pandemic and the risk of isolation, the network started the project Friends in Touch, connecting youth who are deafblind.

In November, the Communication network organized a new series of webinars in 3 different time zones. The topic was booklet 3 (Meaning Making) of the Communication and Congenital Deafblindness series. A lot of families and service providers attended the webinars.

The Ibero Latin America Network celebrated the birthday of Helen Keller with sharing stories of people

who were very important in the field of deafblindness in the region of Latin America. This network has also organized 2 webinars on ethics of guide interpreters and intervenors.

The Technology Network delivered a workshop on technology at a webinar of the European Association of Service Providers for Persons with Disabilities (EASPD). After consulting their members at the meeting, this network has now also started a What's app group.

Finally, I would like to mention the Creative Arts Network, busy with a new start-up. This network is now also actively involved in the Yarn Bombing project.

Just because I don't list all the networks now doesn't mean these networks aren't active. A number of networks, such as the Usher Network, the CHARGE Network and the Research Network, are already busy preparing for the organization of pre-conferences for the Dbl Conference in Canada in 2023.

I would like to invite everyone to visit the Dbl website regularly and to look at the sites of all networks. You will then see why the networks have such a central role within Dbl. It's all about connecting people and sharing knowledge.

Results of the Dbl Communication Committee (ComCom) Activities Survey

**TREES VAN
NUNEN**

DBI NETWORK
COORDINATOR

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The Communication Committee (ComCom) focuses on the outreaching communication of Dbl. In 2019, the ComCom started with the following strategic goal: by 2023, Dbl will have been regarded as a primary source of information and connection for anyone searching for information on deafblindness. Over the past three years, ComCom has taken numerous initiatives and organized activities to work towards this goal. To name a few examples: improvement of the website, Dbl Newsletter, visibility on social media. To evaluate the interest and further expectations of our individual members, we sent out a survey.

Main Results of the Survey

71 members from 29 countries completed the survey. More than half of the respondents indicated that they visit the Dbl website 1-3 times a month.

In terms of data provided by the website, most respondents found information on upcoming webinars and conferences, Dbl Review and news from the networks the most interesting. To a slightly lesser extent, the encyclopedia of deafblindness was considered interesting.

93% of the respondents indicated that information on the website is sufficiently accessible.

The newsletter was experienced by 57% as very informative and by 41% as informative.

With regard to following Dbl via social media, Facebook turned out to be the most used channel (57%); to a lesser extent Twitter (21%) and Instagram (18%).

Talking about the use of Telegram / Dbl Bot to connect with other Dbl members, 84% answered that they were not aware of this possibility.

With regard to the open questions of the survey, good suggestions for improvement were made. It was also indicated that the work of ComCom has significantly improved the reach of Dbl.

Action Points

The survey provided ComCom with important information, and based on the results we formulated the following action points:

- Although 93% of the respondents indicate that information on the website is sufficiently accessible, we must continue working on accessibility: not only in the field of legible and accessible language, but also in the field of the use of international sign language. There may be a role for the Communication Network here. Consideration could also be given to having an individual who is deafblind to read along to assess accessibility;
- It is important for the members of the Latin America countries that the information on the website could be translated into Spanish. At this moment you'll find on the Dbl website instructions to translate the website using Chrome or Google web browser;

- In Dbl Review, as in previous editions, there should again be sections in which different countries and organizations can report about their activities;
- Information from networks on the website is sometimes outdated and needs updating. This item will be on agenda at the network leaders meeting;
- Sometimes people experience loading problems with entering the website. We have improved that with a new security package.

On behalf of the ComCom I would like to thank everyone who completed the survey. With all the information obtained and good suggestions, we have enough input to continue working on our strategic goal and the aim of Dbl at becoming the point of connection in the world of deafblindness!

Deafblindness in Africa: a Continent Sets Much Hope on the 1st Dbi Africa Conference

Africa is, of course, a great continent of many languages and cultures, diverse history and actual situations. Indeed, there is not one Africa, but many. Unfortunately, however, they share at least this one fact: there is little known about the situation of individuals who are deafblind in Africa. So to create something like a picture we contacted individuals who are deafblind and individuals without sensory challenges in the north, south, east and west of Africa and beyond it as well. This article tries to capture the pattern of answers of Alison Marshall, Ezekiel Kumwenda, Mai Ameen, Marianne Riggio, Mary Maragia, Nathasha Parkins-Maliko, Pawlos Kassu, Sian Tesni, and Wilson Masinza. This one thing becomes certainly very clear: the upcoming conference in Kenya is of outmost importance. So if you had not registered for it yet, do it right now!

MIRKO BAUR

DBI, STRATEGIC
VICE-PRESIDENT

WITH MANY
THANKS TO
ALL PERSONS
CONTRIBUTING

Actual Situation

Looking for the data encounters difficulties. For example, the data on prevalence of deafblindness is very limited. The possible reasons of that may imply missing networks, linking players in the field and coordinating their efforts across the countries, regions and beyond.

It's sad to see that many individuals who are deafblind and their families are left behind. They are often challenged by lack of awareness of specific policy, of experts and specialized services, of access to public services and information, of state support, lack or scarcity of research and materials in the

national languages. As other individuals with disability in low and middle-income countries they might be amongst the poorest and face exclusion, stigma, and discrimination. So all in all, their rights are indeed often infringed and their inclusion is often strongly endangered.

However, there are also a couple of hubs that bring hope throughout Africa.

Kenya, the host country of DbI's 1st Africa Conference, certainly belongs to them. Among else, the government of Kenya has consistently recognized the importance of education and training for individuals who are deafblind. The corresponding policy recognizes deafblindness as one of the disabilities. That guarantees learners who are deafblind a right to get qualitative education. Kenya's Institute of Curriculum Development has developed curricula and support materials that suit learners who are deafblind. The Kenya Institute of Special Education, the venue of the conference, offers the first certificate program in deafblindness in the region and Maseno University, the academic conference partner, offers coursework in deafblindness.

You will find talent and passion among individual professionals in all the countries of East Africa, more training programs in deafblindness at Tanzania's Patandi Teachers College and at Kyambogo University in Uganda and throughout long-standing units, largely housed in schools for individuals with hearing loss and supported by the Ministries of Education. In Kenya, there are also several well-established vocational centres for adults with hearing loss and for those adults who are deafblind. And there are active self-advocacy associations for individuals who are deafblind in Kenya and Uganda.

Going farther to the south, you will get to the hub of the African Federation of the Deafblind in Malawi. Malawi is also emerging as a place of many good beginnings. The Montfort Teacher Training College, for example, has started a model classroom for students with visual impairment and multiple disabilities. Already many decades ago, South Africa was the first country to provide a specialized program for those students who are deafblind. Sibonile School also has a long-standing unit for those students who are deafblind. The Kanguru

project serves children with deafblindness and significant disabilities in Johannesburg. This is certainly a model program for this population of children.

Deafblind SA is based in Worcester, home of the Pioneer School, one of the fundamental schools serving those students who are deafblind in the region. There are even some emerging early-intervention programs for children having hearing loss, that serve those children who are deafblind as well.

In the west, Ghana seems to be well positioned to be a hub. There are three programs serving those students who are deafblind. Winneba University has training programs in sensory disabilities. It is the first to welcome a person with complete deafblindness and provide support that they could need to become a successful university student. Ghana Union of the Blind has begun to support programs serving students who are deafblind.

In the Horn of Africa, there is Ethiopian National Association of Deafblind that runs among else a day care centre for children with deafblindness in Addis Ababa. The University of Addis Ababa has been involved in a project related to the research focused on deafblindness in Ethiopia. And through DbI's coordinator, the University has also been the managing center of DbI's Africa Researchers' Initiative to an extent.

Moving up to the north, we see Egypt that is rapidly becoming a hub in this region. Nida Society might be considered the first NGO in Egypt and the Arab world to offer specialized rehabilitation services. Their unit for multiple disabilities and deafblindness offers programs from early intervention to pre-vocational age. NIDA Society has achieved a lot of goals, among them a ministerial decree which declared the acceptance of children with deafblindness and multiple disabilities to special education public schools and the foundation of model classrooms, the training of 140 facilitators for early intervention, 120 teachers, conventions, seminars, and scientific papers. In the next phase of their strategic plan, they will among else collaborate to provide a specialist certificate in multiple disabilities through Alexandria University.



Hope, Uganda, 2021. Photo is provided by courtesy of Sense International

Biggest Needs

According to the answers the biggest needs are the following:

- Rendering help to the individuals who are deafblind in understanding and voicing their rights, needs and demands by themselves as well as empowering their parents, families, and caregivers as their first and most important educators;
- Strategic planning that focuses on strengthening and creating hubs that are centers of excellence in deafblindness, and investing mostly in inclusion, early identification, and early intervention;
- Creation of data, information and awareness which involves research, publications, materials in local languages;
- Presence of local experts in the field and, therefore, of more training opportunities for those interested to work with and for individuals who are deafblind;
- Mobilization of resources, aimed to carry out all abovementioned, and provision of more access, like access to independent living or to assistive devices;
- And much more coordinated efforts through building communities of practice in Africa, and also well exchanged and planned activities of international donor organizations.



Sospeter, Kenya, 2019. Photo is provided by courtesy of Sense International



Inclusive education, Tanzania, 2019. Photo is provided by courtesy of Sense International

Very Important 1st Africa Conference

All of those needs, as well as hopeful answers, can be addressed and pushed forward by the 1st Dbl Africa Conference which makes it indeed a very important milestone. It has great potential to do the following:

- to raise awareness and inform about the situation and the needs of the individuals who are deafblind, especially in Africa;
- to showcase the talents and success achieved so far, especially in Africa, and therefore invite and inspire to further investments that will promote the rights of individuals who are deafblind and their inclusion that will benefit the quality of services for all people in the countries;
- to learn from starting new research and practical workshops and especially from exchange with one another;
- to connect and establish sustainable networks and communities of practice, maybe leading even to a new Dbl Africa Network, next conference and much more coordinated activities.

So let's meet in Nairobi or online on May 12-14, 2022. Be a part and help make a change!

Early Intervention in a Multisensory Environment: Implications and Benefits for Children who are Deafblind

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The Assistance Center for Deaf and Deafblind Children (Centro Assistenza per Bambini Sordi e Sordociechi – CABSS) was founded in 2004 by Roberto E. Wirth. CABSS is the first Italian center to provide early multisensory intervention and mental health programs to deaf and deafblind children 0-6 years old and their families in a multisensory environment. CABSS' mission is to intervene at the earliest time possible in a child's life and give children and parents the specialized support needed to be successful in living informed and healthy lives. CABSS has worked with children with various etiologies over the years, the most prevalent being CHARGE syndrome and premature birth. The organization is directed by Stefania Fadda, a Psychotherapist and Psychologist specialized in Mental Health and Deafness. The team consists of specialists, that passed training both in deafblindness and deafness.

The CABSS Model

The specialists at CABSS developed a model of early intervention for deafblind children. It is a combination of the Canadian Model of Intervention, the Principles of Multisensory Therapy, CBT, and Sensory Motor Psychotherapy.

The driving force of effective intervention and success relies heavily on the active involvement of parents and caregivers. The method focuses on stimulating senses and growth in various developmental areas. (See Fig. 1).

Phases of the Multisensory Early Intervention Program at CABSS

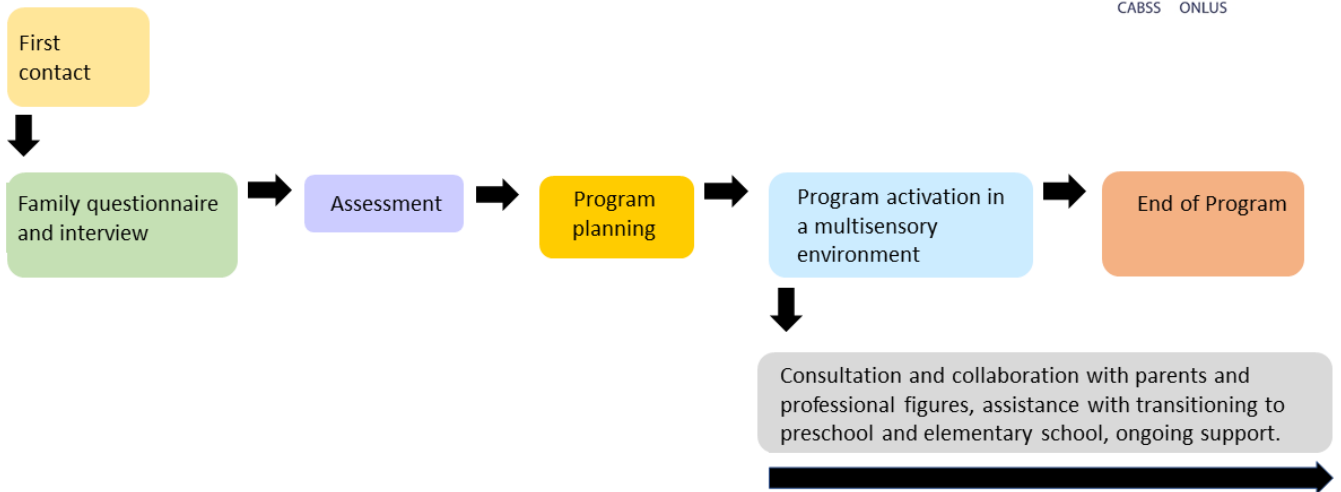


Fig. 1. The CABSS Model of Intervention for Children who are Deafblind

The Multisensory Laboratory

The heart of CABSS is its multisensory laboratory The First Step, created in November 2010. The multisensory laboratory has provided an accessible, safe, and adaptable space that children can freely explore, make

choices, communicate, and have control over their environment. It has highly specialized and innovative equipment to stimulate the senses. (See Fig. 2).



Fig. 2. The Multisensory Laboratory at CABSS

Program Outcomes

Attention. We have seen first-hand children making enormous progress in the area of attention. At the start of the program children are able to maintain their attention on an activity and/or person for 1 or 2 minutes before changing an activity and can tolerate staying in the laboratory for about 25 minutes. In 6 months, children can maintain their attention for about 10-15 minutes on an activity/person and can stay in the laboratory for about 50 minutes. Over time, if the children are healthy and don't experience any major life changes, we see them making the shift from being able to attend to one isolated stimulus to being able to tolerate more than one at a time. As they form a bond with intervenors, they begin to engage in activities that involve turn taking, joint attention and their visual, auditory, and tactual attention increases considerably.

Self-regulation. The multisensory materials and equipment along with the child-guided approach in the laboratory have helped children to self-regulate. In the laboratory, children have freedom to choose how they would like to position their bodies to receive stimuli. Parents and intervenors work hard in becoming tuned with their emotional and physical needs. We have seen that all of these elements have been key in maintaining an optimal state for learning, for children

finding ways to cope, solve problems, or adjust to external/internal factors.

Communication abilities. The laboratory is very flexible, and we can either move around or bring equipment to a child and adjust lighting/sound which makes visual and auditory information highly accessible giving them the best opportunity to receive input, reach out and interact with stimuli. A child also has many opportunities to receive tactile information by interacting with the toys, utilizing communication tools, or receiving input from the hands of an intervenor. We utilize a total communication approach which also provides an accessible environment that stimulates communication.

Parental involvement. Parental involvement has made what we do so much more meaningful. They can see first-hand their child's progress, discover new things about their child and have someone to share their experiences with. They learn together with their child, and they are encouraged to apply what they learned at CABSS in the home environment. Soon after parents start the program, we see that they exhibit lower levels of stress, acquire competence in understanding how and what their child is communicating and can respond effectively. As the program progresses, we see most parents becoming strong advocates for their children.

Assessment of Communication in Children and Adults who are Deafblind

This is the sixth in a series of articles about the assessment of children and/or adults who are deafblind. In this article, we will specifically address assessment of communication, with emphasis on individuals who are pre-symbolic to early linguistic communicators. We will begin by briefly sharing communication assessment content from earlier articles within this series. We will then present content on a commercially available instrument, *Communication Matrix* (The Communication Matrix Foundation, 2022, communicationmatrix.org), signal and touch cue dictionaries, and communication profiles.



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Reviewing Communication Related Content from the Assessment Series

Before introducing new content, we would like to review communication assessment content from the assessment series. The third article in the series (Bruce et al., 2020) was devoted to presenting a method for teaching the van Dijk approach to assessment. It includes resources and references to support team members to implement this child-guided approach to dynamic assessment. The communication sections of the *Hawaii Early Learning*

Profile (HELP; Teaford et al., 2010; Warshaw, 2006) and *Behavioral Characteristics Progression* (BCP; Vort Corporation) assessment instruments were covered in the fourth article (Bruce & Bianco, 2021). The fifth article (Bruce & Moore, 2021) addressed the communication sections of the *Developmental Assessment for Individuals with Severe Disabilities*, Third Edition (DASH-3; Dykes & Mruzek, 2012) and the *Vineland-3* (Sparrow et al., 2016).

Communication Matrix

The *Communication Matrix* was developed by a team of speech pathologists, teachers, researchers, and families of individuals who use communication forms/modes other than speech to create a detailed evaluation system of nonverbal communication (Communication Matrix Foundation, 2021). The online platform for the *Communication Matrix* can be administered in a variety of contexts, enabling assessors to record potential differences in a student's communicative behavior at home and at school (Quinn & Rowland, 2017).

The *Communication Matrix* analyzes two of the major aspects of communication: the reasons (also known as communication intents or functions) that individuals communicate, and the behaviors which they use to communicate (Rowland, 2012). This instrument measures nine types of communicative behavior: body movements, early sounds, facial expressions, visual behaviors, simple gestures, conventional gestures, conventional vocalizations, concrete symbols, and linguistic behaviors (Rowland, 2011; Rowland & Fried-Oken, 2010). The focus on the inclusion of a variety of nonverbal communication behaviors demonstrates the aptness of the *Communication Matrix* for assessing

students who are deafblind with a wide range of communicative abilities. The online forum suggested by Quinn et al. (2019) would be beneficial to inexperienced evaluators by providing them resources to supplement their knowledge. The forum is useful in supporting evaluators to recognize subtle communicative behaviors.

The *Communication Matrix* also supports the team to determine each individual's current level of communicative behavior. The first four levels of communication development: (1) pre-intentional, (2) intentional behavior, (3) unconventional and (4) conventional communication – are generally the usual developmental phases of typically developing children (Rowland, 2011). The next level, which implies (5) use of concrete symbols (including objects and pictures), may be a critical developmental phase for individuals with disabilities who require additional support to grow from the use of concrete representations to more abstract representations. The final levels are (6) use of abstract symbols and (7) language (Rowland, 2011). Identifying each individual's level of communication coupled with their demonstrated communicative behaviors can support the development of individualized communication interventions.

Signal and Touch Cue Dictionaries

Some individuals who are deafblind express through communicative behaviors that are not recognized by others. An important part of assessment is to identify each individual's unique expressive communicative behaviors and then to create a guide to support others to be responsive. This responsivity will reinforce and shape further communicative efforts by an individual who is deafblind. Signal

dictionaries are simple visual tables with columns that list the individual's subtlest communicative behaviors (including home signs), the probable meaning(s) of each communicative behavior; and what communication partners should do and say/sign in response (Bashinski & Bruce, 2014). See an example of an entry in a signal dictionary below.

Communicative Behavior of an Individual who is Deafblind	Probable Meaning	Communication Partner Responses
The individual taps wheelchair tray repetitively (paired with neutral or positive expression)	I want you to put that on my wheelchair tray. (This could be something the individual has just touched or sees in near space).	<p><i>Verbal response:</i> "You want ___ on your tray."</p> <p><i>Action:</i> Place the desired object on the wheelchair tray.</p>

Similarly, it may be helpful to create a touch cue dictionary. Touch cues are physical cues provided on the body of the individual who is deafblind to support them to predict and remember an associated action that comes after the cue (Bruce, 2005). Touch cues help individuals who are deafblind to know when another person wants or needs to physically interact with them. These cues are especially important for individuals without functional vision. For example, the team (including the family) will need to agree on a touch cue to be used before sharing hands

with an individual who is deafblind. They may need to reach consensus on a cue to be used before lifting and positioning, among others. The team should agree on the touch cue and on the words or signs to be associated with it. After providing the touch cue and associated communicative message, the team members should pause to allow the learner time to process the meaning. Touch cues support the emotional security of individuals who are deafblind by making their world just a bit more predictable. See an example of one entry in a touch cue dictionary below.

Touch Cue	Meaning of Touch Cue	Words and/or Signs to Pair with Touch Cue
Two gentle taps on the back of individual's left hand (followed by pause for their response)	I'd like to share hands with you	Verbal: "Hands?"

Communication Profiles

Teams may want to develop their own communication profile that includes detailed information about the expressive and receptive communication of an individual who is deafblind. Such profiles may serve as both an assessment instrument and a way to represent assessment findings. Communication components may include the findings from the *Communication Matrix* (The Communication Matrix Foundation, 2022) and other communication assessment instruments, as well as information about contexts, activities, routines, and supportive communication partner behaviors. A holistic communication profile might include the individual's level of play and performance of pivotal developmental milestones such as joint attention (including non-visual joint attention), object

permanence, imitation, means-end, problem solving, discrimination (visual, auditory, and tactile), and categorization (Bruce, 2010a). It may also share information on how the individual who is deafblind shares affective states, makes authentic choices, and uses repetition and repair. These profiles may include a final section on recommendations for practice. Thus, they are useful when providing consultation to teams. Please see Bruce (2010b) to review one format of a holistic communication profile, as well as an example of a completed profile on one learner who is deafblind. Holistic communication profiles support the team to think beyond communication in isolation to the connections between communication and other domains of learning.

Conclusion

Communication is a critical area of development and intervention for individuals who are deafblind across educational, residential, and vocational settings. Comprehensive communication supports are built upon thoughtful assessment of the individual's receptive and expressive communication strengths and needs, with consideration

paid to other domains of learning that impact communication. Dictionaries and profiles provide a record of the current communicative behaviors of individuals who are deafblind, thus supporting teams provide individually appropriated communication supports.

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Paths to Employment

Acknowledgements

The project Wege in den Beruf is funded by the Aktion Mensch Foundation.

Introduction

In Germany, individuals who are deafblind express their interest in a professional activity, but there are no corresponding training and rehabilitation offers. There are only a few individuals who are both deafblind and employed. That is to change with the project Wege in den Beruf (Paths to Employment). In a unique cooperation and with the support of the Aktion Mensch Foundation,

the educational and rehabilitation programs of the Nikolauspfl ege, Foundation for Blind and Visually Impaired Persons, the German Deafblind Association and the SFZ Förderzentrum GmbH are to be expanded to include specific offers for those individuals who are deafblind. The project has been running since June 2020 and we can provide the first results from the carried out needs analysis.



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Wege in den Beruf Project Summary

WEGE IN DEN BERUF



Fig. 1. The logo of Wege in den Beruf

- Project duration: June 1, 2020 – May 31, 2025;
- Cooperation between the Nikolauspfl ege, Foundation for Blind and Visually Impaired Persons, the German Deafblind Association and the SFZ Förderzentrum;
- Implementation of the vocational rehabilitation services following the project in Hannover, Stuttgart, Berlin, and Chemnitz;
- Other cooperation partners: Prof. Dr. Andrea Wanka (Heidelberg University of Education), German Federation of the Blind and Partially Sighted (DBSV), Legal Aid Office for Persons with Disabilities (RBM);
- Funded by Aktion Mensch Foundation;
- More information available at:
 - www.wege-in-den-beruf-tb.de
 - www.facebook.com/BarrierefreiInDenBeruf
 - www.instagram.com/wegeindenberuf

PROJECT WEGE IN DEN BERUF, NIKOLAUSPFLEGE

FOUNDATION FOR BLIND AND VISUALLY IMPAIRED PERSONS

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On the Current Situation of those Individuals who are Deafblind

The individuals who are deafblind experience extensive restrictions in almost all areas of social participation. The dual sensory loss has major impact on social interactions and communication, orientation and mobility, information acquisition and, thus, fundamentally on coping with everyday life (Kaul et al., 2014). There are few accessible opportunities for individuals who are deafblind to take part in social life without support (through assistance or technical aids) (Kaul et al., 2014). With regard to professional participation, acquired deafblindness often leads to retirement at the still working age (Kaul et al., 2014). Young adults who are deafblind often have difficulties finding suitable vocational training after leaving school. In a study on the living conditions of those individuals who are deafblind in Switzerland, 38 percent of the participants

of working age were employed, and around a third of these are not employed in a competitive work environment, but in a sheltered workplace such as a workshop for the people with disabilities (Adler et al., 2011). The following effects of (acquired) deafblindness are described in various qualitative studies in which people with acquired deafblindness were asked about their life situation: “being dependent on help”, “having to find new strategies for coping with everyday life and constant adaptation”, “communication difficulties”, “loss of work”, and “negative impact on psychosocial well-being” (Olesen & Jansbøl, 2005; Schneider, 2006; Goransson, 2008; Adler et al., 2011; Gullacksen et al., 2011; Fletcher & Guthrie, 2013). Some studies also find a higher prevalence of mental health problems in individuals who are deafblind (Dammeyer, 2014).



Fig. 2. Tactile communication. © Marcel Domeier

Need for Specific Rehabilitation

The described effects of living with deafblindness stress out the need for specific rehabilitation services for this group. This is also the conclusion of the studies cited above on the living situation of individuals who are deafblind. Although there are specific rehabilitation measures, services or aids for people having only visual or hearing loss, they are not sufficiently compatible for individuals with dual sensory impairment. The strategies, aids and procedures from the rehabilitation practice of a single sensory loss are mostly based on compensation through another distant sense and are therefore not applicable for individuals who are deafblind (Brabyn et al., 2007). The

group that needs specialized rehabilitation services includes, for example, young people having hearing loss who are unable to find a suitable training occupation due to visual impairment that sets in at the end of school or is worsening (Bunck & Jacobs, 2001). They need a vocational rehabilitation service in order to learn skills and strategies for dealing with new dual sensory loss and then to start appropriate vocational training. Adults who have already finished job training and are employed also belong to the target group for vocational rehabilitation services if an occurring or progressing sensory impairment causes problems at workplace.

Goals of Vocational Rehabilitation

The ultimate goal of vocational rehabilitation is financial, social, and political equality (Ruzenski, 2019). Employment results in particular and significantly in equal financial opportunities. However, it also shows that a job is one of the most important sources of satisfaction of social and psychological needs for people of working age (Blustein, 2008, cited from Ehn, 2020). Employment among people with Usher syndrome I and II results in fewer psychological health problems (Ehn et al., 2016; 2019). In addition, for people with Usher Syndrome II, the workplace is the most important area for social interaction next to the family (Ehn, 2020). Apart from the goal of employment, a specific rehabilitation service helps to maintain or regain independence in shaping one's life. In addition to vocational rehabilitation, these services also imply social rehabilitation (Bunck & Jacobs, 2001).

Fig. 3. Orientation & mobility training.
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Development of Specific Rehabilitation Services in Germany

The aim of the project Wege in den Beruf (Paths to Employment) funded by the Aktion Mensch Foundation is to develop specific vocational rehabilitation services and vocational training opportunities in Germany. They

should be tailored to the specific needs of individuals who are deafblind. In order to ensure this accuracy of fit, the project carried out a comprehensive needs analysis. First, in a literature review, 75 studies and practical

reports on the subject of (vocational) rehabilitation and employment in the context of deafblindness from the last 15 years (published between 2005 and 2020) were collected and studied. Several topics appeared: the high – not yet adequately covered – need for psychosocial support (Olesen & Jansbøl, 2005; Göransson, 2008; Bodsworth et al., 2011; Wahlqvist et al., 2013; Ehn 2020) on the one hand, and the need for support when looking for a job and at the beginning of employment, combined with accompanying training directly at the workplace (Watters-Miles, 2014; Shadrack & Eten, 2019) on the other hand. Comprehensive and holistic (functional) diagnostics and assessment should be carried out at the beginning of every rehabilitation process (Olesen & Jansbøl, 2005; Watson et al. 2008). As deafblindness often is a progressive sensory impairment, it is necessary for this target group to enable recurring participation in services and process-accompanying recurring diagnostics (Ellis & Hodges, 2013; Wahlqvist et al., 2016). With regard to the skills of professionals in rehabilitation services, mastery of sign language or as many forms of communication used by individuals who are deafblind as possible was mentioned as an important prerequisite for the success of rehabilitation services. In order to approach the question of how many individuals who are deafblind require vocational rehabilitation services in Germany, around 450 institutions (schools, specialist integration services, advice centers, vocational training centers, self-help groups and associations) from two fields of visual and hearing loss were asked to participate in an online survey. In the survey, the institutions could anonymously report the number of clients/students/apprentices/members with deafblindness. 748 individuals who are deafblind were reported. Considering the assumed duplications, we expect that in Germany there are around or at least 630 individuals who are deafblind and who need vocational training or rehabilitation opportunities. Evaluating the feedback from schools – the response rate was at 50 percent – around 30 young adults who are deafblind graduate from school every year. There is probably the need for pre-employment education and vocational training.

In addition, the participating specialist integration services reported 273 individuals who are deafblind seeking for an advice in the year 2020, eight of whom have so far been involved in further rehabilitation services. In the qualitative part of the needs analysis, interviews were conducted with twelve representatives of the target group. Among them, there were young adults who had just finished school, as well as employed and early-retired people. There was also a heterogeneity concerning the language used (spoken or sign language). Here, among other things, the need for recurring training and a unified form of training services, psychosocial support, support with professional orientation and job searching as well as support and training at the workplace was mentioned. It was also shown that despite the need for individualized offers, the exchange with peers plays a central role. In addition, many interviewees demanded an opportunity to provide the working environment with a better understanding of the effects of deafblindness, for example through awareness-raising workshops.



Fig. 4. Target groups

By 2025, based on this needs analysis and supported by a comprehensive participation process, vocational rehabilitation and training services should have been created. The aim of the project is subsequent implementation of services and permanent financing so that every individual who is deafblind in Germany is eligible to participate in these rehabilitation services.

International Exchange

In course of our Call for Exchange of Information and Best Practice Examples (see Issue #64) and contact abroad, we found that the topic of employment and work in the context of deafblindness is relevant not only in Germany. We got in touch with Eikholt National Center on Combined Vision and Hearing Impairment/Deafblindness in Norway. They are also currently dealing with the topic and have recently published

the study *At Work with Dual Sensory Loss* in Issue #65 (Johansson, Olson & Lund). In September 2021 we had a possibility to visit our colleagues at Eikholt to exchange ideas and experiences. We plan to continue our exchange and possibly expand it to other interested people and institutions that are motivated to work together on the topic of employment and work. There will be more information to come.

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Solitude as an Analytical Concept to Understand Young People's Accounts of Living with Usher Syndrome

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article. We are grateful for their work, which made this article possible. We also thank seven brave young people, who gave us insights in their life.

Introduction

Growing up with Usher syndrome influences the life path in various ways. However, researchers have seldom investigated young peoples' own narratives and how they perceive their own upbringing and life with Usher syndrome. Their perspectives are all too often overlooked, even if it is crucial to understand the needs of those affected (Jaiswal et al., 2018). This is particularly problematic when examining young people and how they live with acquired deafblindness. They are in a phase of life during which they have to cope with issues of identity, choosing an

educational path and many other decisions present in youth life. This is a challenge for young people living with Usher syndrome as they have to adapt multiple times due to the progressive loss of sight and hearing. Studies have shown that people with Usher syndrome are at a higher risk of developing depression, anxiety, and stress. There is also a greater risk of suicidal ideation for the group (Wahlqvist, C. et al., 2013; Wahlqvist et al., 2016). These studies emphasize the need for deeper knowledge about qualitative experience of living with Usher syndrome.

Study

This article is based on data produced in a joint study between ISHD and CFD. Seven young people (13–29 years) were interviewed. The interviews were based on a semi-structured interview guide. Six interview participants were

female. 10 analytic themes identified in the study are presented in an earlier article of *DbI Review* (Pedersen, 2020). The results from the study are presented in two reports (Pedersen et al., 2021; Hansen & Toldam, 2021).

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New Emergent Theme: Solitude

In this article, we investigate the analytical theme of solitude. Our argument will be that solitude as an analytical concept can contribute to understanding experiences of young people living with Usher syndrome.

Solitude is often used synonymously with loneliness. However, in this article a distinction between these two concepts is central. *Solitude* is the self-chosen state of being alone. This is often meant literally, but in this article it also includes the state of

keeping one's thoughts to oneself. Whereas *loneliness* is the emotional response to a perceived isolation (Weinstein, Nguyen & Hansen, 2021). This is when individuals feel they have no one around to support them. No friends, family or other company. Feeling lonely is undesired, whereas solitude can be a place to reflect on one's thoughts, mentally digest experiences and a way of preserving one's energy. In this study, solitude presents itself as both a state of mind and as a coping strategy.

Being Alone with One's Thoughts and Worries

The interviews indicate that young people with Usher syndrome often feel alone with their thoughts and worries. They feel reluctant to talk with friends, family and sometimes also professionals about the limitations or worries that the acquired deafblindness gives them. Instead, several participants use strategies of avoiding and hiding.

The thoughts of participants about their current situation and their future situations differ, but they share the fact that they feel relatively alone with their thoughts. They hardly share them even with their closest relatives. In this context, being alone with one's thoughts means that the way young people feel their situation is so unique that none of their friends or family really will be able to understand them.

Family

Some of the young people in the study refrain from sharing their thoughts with their parents in order to avoid making them sad. Linea is an example, "*when my parents found out [ed. about Usher syndrome] it wasn't very funny for them. They actually got really, really upset. When I talked to my dad about it, he started crying. Then I started crying and then we couldn't stop crying*". Later she elaborates about how her parents feel in regards to her Usher syndrome, "*Because they both feel a bit guilty, and it upsets me when they say they feel like it's their fault*". Other participants tell about how they were comforting their parents, when the diagnosis was given.

Solitude may become a strategy for a young individual. Avoiding to talk about Usher syndrome in order to protect parents from being sad. Another interesting observation was made in connection with siblings. Three of the participants have siblings with Usher syndrome. None of them discusses or shares their emotions about the dual sensory loss with their siblings. Thus, in this context, solitude materializes itself in the way of avoiding the topic to protect the feelings of one's family. Here we see a young individual choosing solitude as a protection of someone else's feelings and grief.

Friends and Classmates

The experience that the ones around you can react to your problems with fright or sadness is the one Tannie shares, although she reflects upon it in the context of friendship

rather than family. She explains the importance of having a close network of friends, where she can be honest about her concerns and sorrows, "*It is important to have a*

network where you can tell things are rough without people thinking, 'Oh no, are you going to break down?' Because that's not what it's about". In the study this kind of friendship is rather unique to Tannie. The other participants say that friends know about their condition, but aren't involved in their concerns about the future, etc.

The strategy of solitude and keeping quiet to friends is grounded in other considerations than those about not talking to one's parents. Sofia explains, "I do not feel that I talk so much with my friends about this. When I'm with my friends, I just want to forget about it and not to talk about what it is, that I have".

For some, it is a question of who you want to share these thoughts with and thus solitude is a way of creating a space free from worries that follow with Usher syndrome. For others, it is a question of not wanting to show weakness or drawing attention to an issue they feel makes them appear different and therefore something they keep entirely to themselves. In these situations, the boundary between solitude (a strategy) and loneliness

Professionals

The young people in our study have contradictory experiences with professionals they have dealt with in relation to the Usher syndrome. For some, the help of professionals has prevented the persons' solitude to turn into loneliness. For others, the actions of professionals can – from a young person's perspective – push them into solitude. Sofia shares the following experience. Being a pupil, she felt exposure of the professionals around her, "At that time, when I was at that age, I wasn't ready at all! I didn't want anything. I didn't want to be exposed in that way (...) If you aren't ready, then it's a bad experience, and you get trauma, and you start to feel very lonely".

A major point in the study is the young people's determination to define an identity

(feeling all alone with one's thoughts) crumbles. Frida says that the idea of not showing weakness was a deliberate strategy for her as a young teenager. To prevent anyone from bullying or mocking her, she built up a bossy persona to protect herself from being hurt, "To survive this I'll have to adapt and I'll have to create a shield around myself that will deter people from bullying me. And I surrounded myself with friends that might be a little harsh and dominant". With this strategy she kept all thoughts about Usher syndrome to herself, thus securing control over information about herself and her situation. Here solitude was used as a strategy. Frida tried to avoid being pushed out of a group by withholding certain information. In her own words this was successful, since she did not experience more bullying than other classmates.

Solitude in this context crystallizes in trying to hide the syndrome and its consequences in daily life. This is in order to protect oneself and in trying to maintain an identity, which is not defined by the syndrome.

independent of their disability. In their perspective, Usher syndrome should never be the defining feature of an individual. This can explain why young people sometimes choose to withhold their worries about deafblindness.

There can be conflicting perceptions of what is the best way for a young individual to deal with the acquired deafblindness. None of the professionals around Sofia or others meant to do any harm. Their focal point was probably to de-tabooise the dual sensory loss by speaking freely about it. A strategy which for the young individuals in question felt like having a spotlight directed towards the very part of them, they struggled the most with.

Consequences of Feeling Alone with a (Potential) Frightening Future

The analysis so far highlights that people with acquired deafblindness can choose

solitude as a strategy to overcome the challenges they experience with their dual

sensory loss. This strategy will in some situations be beneficial for them. And yet, there is another side of solitude, in which this strategy becomes problematic and reflects the avoidance of young individuals' own process of recognition. Here it might be helpful to use the concept of psychological flexibility, which describes how a person adapts to shifting demands, changes mental resources and perspectives, and finds a balance between competing demands (Kashdan & Rottenberg, 2010, p. 866).

One example from Frida shows the following, *"When you are at this age, just about to be a teenager, and you enter something like an identity crisis. At that point it is so important that you get to talk to a psychologist – or just someone – even if you say it isn't important and 'I can handle this'. You shut down, shut out the world, and find yourself in a total conflict with yourself, the world around you and your disability too".* This "conflict with yourself" as Frida gives words to is crucial to understand the process that young people with Usher syndrome go through. How do you balance the desire of being a typical teenager with wishes, dreams, need for autonomy and self-determination when you have Usher syndrome that possibly will

Implications for Practice

Solitude can be seen as a key concept in understanding some of the issues, young people have in living with Usher syndrome. Loneliness is often used to describe the negative psychological state of isolation, whereas solitude offers broader understanding of being alone. Through the concept of solitude, being alone can both be viewed positively and negatively. Understanding solitude as a strategy in coping with deafblindness might be meaningful for professionals. Solitude can be a way of achieving agency and autonomy. It enables people with acquired deafblindness to shift perspective and to cope with different issues. But being alone with one's feelings can turn into loneliness, and long-term avoidance of support from family, friends

make you dependent on deafblind services and impact your future? Solitude might be a possibility to escape from having to deal with the shift of perspective. This strategy can also be beneficial on short-term, however, as Frida mentions, guidance and psychological counselling might be necessary in order to prevent more pathological conditions like depression, anxiety and stress. Understanding these different feelings and processes is important for professionals to support young people with Usher syndrome.

Psychological flexibility is also mentioned by Ehn et al. (2019). Though they look at older participants (20–64 years), there are similarities between their study and this study. Ehn et al.'s study focuses on how the participants were trying to balance competing needs – trying to live their life, while adapting to the conditions posed by the syndrome and dealing with the emotional aspects of Usher syndrome. For some, avoidance was a strategy, *"They simply avoided situations where deafblindness was in focus and did not spend more time than necessary talking about it"* (Ehn et al., 2019, p. 10). In this case Ehn's focus on escapism resembles our use of the term of solitude as a strategy in coping with acquired deafblindness.

and professionals might result in a higher risk for more pathological conditions.

It is important to recognise and respect the self-chosen solitude as a deliberate strategy, but also be aware, if it has the potential to turn into loneliness. Ensuring timely support, when a young individual is ready to receive it, is rather difficult. It does require professionals with patience and ability to adapt their support to the needs of young people. Finding ways to overcome the loneliness must be an important consideration for the professionals working with young people living with acquired deafblindness. It is important that it is done in such a way that it does not transgress the personal boundaries and limit the autonomy of a young person.

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Write Some Words for the People who aren't Familiar with Deafblindness

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Acknowledgments

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- Smitha Chakravarthy (interpreter)

In order to raise public awareness during the yarn bombing initiative in June 2021, we asked some individuals who are deafblind, their families, and their companions to write some words for the people who aren't familiar with deafblindness. These are the testimonies they wanted to share:

Ladies and gentlemen,

I was unfortunately unable to attend this very special event but I would certainly like to share my experience with you.

I'm 37 years old and I'm a mother of 3. I'd like to talk to you about my deafblindness, a condition not many people in France are aware of.

The degree of visual impairment is very variable. My own vision is almost non-existent, but I have almost clear central vision when my retina swelling doesn't bother me too much! I'm a human being just as much as the next person.

How is the one supposed to behave when confronted with an individual who is deafblind?

Depending on the request made by the individual who is deafblind,

the one should adapt ie. position oneself near or away from the person and communicate using French sign language or tactile sign language.

Here's an anecdote: I'm visually impaired and I use a white stick to move around. But sometimes, I arrive at a doctor's waiting room and pick up a magazine to read. And that shocks some people!

I'd like to tell you the following. Please don't judge a person without getting to know them. Don't show them any pity. Have the courage to approach them!

Deafblindness is not the same thing as total visual impairment. Just as it is not the same thing as total deafness.

Thank you for listening.

Nathalie Macé

Deafblindness??? What is that?

When you hear this question, you're at a complete loss...medical experts often talk about a form of autism and yet, when you observe your child and their attitude, you know that's not it.

Deafblindness can be very different depending on the time when it appears. And painfully, you try to communicate with the person.

Which moments are the painful ones? What do these gestures mean? What should you do for better communication?

As parents, we don't know everything but we do know our children and we do everything to help them make progress. Yes, I do say "progress" and especially, we do everything to help them live as normally as possible.

The acquisition of communication and comprehension is a never-ending process and especially does not stop at what's called "adulthood".

For the person's well-being, it is imperative that we continue the learning about life and everything associated in order to live.

Pascale Algéri, Arlene's Mother

My little extraterrestrial, you live on a planet where the shadows on the ground are precipices that you avoid with caution, the stones are traps that try to destabilize you at every moment.

You come from a world where walls like to be caressed.

On your planet, you speak a language that must be earned and that only a few privileged can understand. On your planet, small

problems are all but fuzzy, courage is a daily affair.

On your planet, one takes the time to live, to learn and to love.

On your planet, I thought you were surrounded by people, yet alone. But I discovered that this wasn't true.

I discovered this world of deafblindness with concern, but as always, you reassured me. I love you, my extraordinary one.

Leslie Sévignac, Laura's Mother

What can I say in just a few words?

Deafblindness is a very specific disability, which has various origins and forms, disrupts movement, communication, access to information and is very tiring.

My condition constantly evolved and very often isolated me socially, compelling me to frequent adaptation. I had to shift from denial to acceptance and adopt humour as my protection mechanism. Hearing and technical aids aren't a silver bullet. Hearing sound cannot compensate for the lost vision of a blind person. Vision cannot compensate for the loss of hearing in a child who was born deaf. To add to this, my problems with balance complicated matters even further.

I'm not asking for either pity or disdain. I want to be a full citizen. I can't bear hand-outs; I want the means and the most comprehensive universal accessibility for responsible autonomy.

Currently, the main challenges I face include independent and safe movements, digital access (especially internet websites, new technologies), shopping for groceries and cooking meal.

Despite my cochlear implants, there are times when I can go completely deaf and blind (full deafblindness).

Since I can no longer see fully, I miss the opportunity to visually admire (and nothing more!) my interlocutor's charm.

While I accept that I can no longer see, I do not accept the absence of or haphazard provision of access (to TV and film material, culture, tourism, political life).

When can we hope to have a person with dual sensory impairment as a President of the Republic?!

Vincent Jaunay, Monique's Companion

My partner is deafblind. I myself have turned deaf. But I can speak.

My partner's deafblindness has changed a lot since 2005. Thanks to a cochlear bi-implantation, he has good hearing compensation, allowing him to use technical aids (voice synthesis for example) to compensate for his quasi-total blindness. I've kept track of these changes. I have learnt to guide him outdoors and I remain attentive indoors. He has shown very few moments of discouragement. He has shown a lot of willpower to find the human and technical aids necessary to continue his work and his projects. Even though he can no longer see the landscapes, he enjoys travelling and guided tours. I guide him, describe the places to him as best as I can, help him to detect the layout of the room.

It is difficult to find aides on an occasional basis. In 2019, I was unexpectedly hospitalized for 2 months. He somehow managed to obtain assistance for indispensable things such as meals, shopping, and household chores.

One major thing that's missing is an alarm that would help telling the time, detect fires or water leakages, especially at night when he removes his implant processors. When he isn't wearing them and when necessary, I write on his hand.

He has his bearings in his flat where he can move around without a stick, provided that there is a specific place for each object and that each object is in its place. The cupboard doors must be closed. The doors to rooms must be either open or shut. When he enters a room I'm in, I indicate my position to him. He tries to help me as much as possible, by laying the table, hanging the laundry out to dry, putting away the groceries...

We complement each other. He lends me his ears in some situations. I lend him my eyes.

It's hardly anything, but I miss his compliments when I come back from the hairdresser's or when I wear something new!

Monique Perrocheau, Vincent's Companion

Talking about deafblindness in a few lines isn't easy. It is a term that is both vague and specific at the same time.

First of all, deafblindness is defined as a dual sensory impairment in vision and hearing. It doesn't necessarily mean deaf and blind. In my case, I have vision and hearing loss. At first glance, it's not necessarily visible because it's an invisible disability, like 80% of all disabilities.

In order to better illustrate my deafblindness, I've chosen some very concrete examples from my daily life.

I have hearing devices in both my ears but sometimes, in conversations, when I believe I've understood the question, in fact, I am

completely clueless! So please don't get annoyed if I ask you to repeat yourself. My visual field is also gradually reducing but my visual acuity has remained rather unaffected. This means that I cannot see in the periphery: my eyesight is like seeing through a keyhole. So, yes, sometimes, I trip on the street, because of a footpath, a pole (which are often not compliant with standards...) and I can swear that it's not because I'm drunk! Also, if I don't shake your hand, it's not because I'm being snobbish, it's rather because your hand is not in my visual field. I can see a ship far away in the sea but I can also look for an object that has fallen at my feet for two hours! And wearing glasses doesn't make things any better! When I use my stick, if you

want to help me, introduce yourself and ask me if I need help. Don't treat me like a child. If I sit down to admire the scenery, check my phone or read, don't assume I overuse the cane. In my case, the walking stick actually calls attention to me and prevents me from bumping into you. A walking stick doesn't necessarily signify a blind person.

Being able to hear less well and seeing fewer things multiplies the challenges in my daily life. I could give you so many more examples...

But thanks to the unwavering support of my family and friends, I can adapt to my disability every day. I hope that my small presentation will have given you greater awareness about deafblindness.

Angélique Mornet-Hocquard

I had obviously never imagined being the mother of a child with disability, a child who is deaf-blind, who has both vision and hearing loss.

And of course, this is something that I wouldn't even have been able to imagine. I love to read and when Solal was just a baby, I'd resigned myself to the fact that this was unfortunately one of the things we would never share. But that wasn't true. 5 years later, he came to me asking for stories, and he leafs through the pages of books with great interest.

Being parents of Solal and dealing with deafblindness implies for us, on a daily basis, lending our ears to this interested and brave little boy and, together with him, discovering other ways in which to experience his body and the world...

To observe him, to adapt ourselves and to adapt the environment, to get creative and also to know how to surround ourselves by enthusiastic and committed professionals.

When Solal was a newborn and for a long time afterwards, it seemed natural to me to use the tactile sense, to massage him to the tips of his fingers and toes to make him aware of the potential and the limits of his own body.

When he was a few months old, we would lay him on top of or under a grand piano and we thus realized that Solal could hear music, in his unique way, with his whole body. Later, I would find him lying on the wooden floor, like a little Sioux Indian, to feel the vibrations of the ground which communicated our movements to him.

He would explore his toys with his hand with great concentration but with a distant look in his eyes. It was as if he had eyes in his hands.

At the day-care centre, he would smell the necks of the nurses to recognize them from their perfume or would touch a distinctive ring or a pendant.

Often we would find him placing his hand on our vocal cords to try to understand what it meant to speak.

And then, we had heard Solal say, "banana" before he said "mummy" or "daddy" because he loves to eat. Our daily life is like a musical comedy show which can sometimes start at 4 a.m. with an improvised solo performance of "A la claire fontaine" or "Il était un petit navire".

Solal began to walk, run and jump later than other kids but it was always with satisfaction of a mountaineer who had climbed the Everest.

Solal walks around in this new space without ever bumping into things because he is careful and deliberate and uses the little vision he has in his right eye to the best of his ability. But he has also developed faculties with other senses that we don't possess.

We, his parents and his brothers, are thrilled with his small daily victories. He teaches us that we can be both, fragile and strong at the same time. The logistics aren't always simple. There is still a lot of inequality with regard to disabilities; a lot of inquisitiveness, which is often well-meaning but sometimes can be otherwise.

But we like it when people ask us questions. There are no taboos and it is important to speak about deafblindness and daily lives of our child and our family.

Laëtitia, Solal's Mother



Deafblindness is my Space

CONVERSATION
HELD BY
**VLADIMIR
KORKUNOV**

Alena Kapustyan, Moscow, Russia. About childhood and family, hearing and vision loss, Sergiyev Posad residential care facility, Touchable performance and wise deafblindness.

The deafblindness makes things distracting of the world go – in terms of both emotions and perception. It takes away and grants, brings a person back to themselves, makes them peer into life more thoroughly all at the same time. Perhaps, that is why Alena Kapustyan calls it wise and doesn't blame it for anything.

Alena lost her hearing and vision in the childhood, came rough circle of Sergiyev Posad residential care facility, absence of friends and of acquiring them over again. It has toughened her, but it has never made her acerbate. In terms of interpersonal relations, she is a cordial and empathic person, that wants both to understand and to explain to someone else.

By the age of 24, she has managed to do lots of things: she became an actress of Touchable performance, carried a flag at the Paralympics closing ceremony in Sochi, entered in and is now successfully studying at college, takes part in performance art events, writes poems, stories, and essays...

Our interview started with one of them, when Alena wrote, "saying that you've got acquainted with a deafblind artist or sculptor is wrong; it is correct to say, "with an artist or a sculptor", and to mention that they are deafblind further, so that the diagnosis isn't put in the first place, and the personality – in the second".

It seems to me, we managed to do it in our interview.

Alena, tell about your childhood. What family were you born in?

I was born in a small village in Moscow region.

My mother, Yuliia Alekseevna, worked as a manufacturing engineer. My father, Aleksandr Vladimirovich, worked as a cash-in-transit guard. Unfortunately, my parents got divorced when I was two years old. Father would often take me to his house and would give me a ride to school in Sergiyev Posad on Mondays. Later, mother met her second husband, Evgenii Nikolaevich. My younger brother Daniil was born then.

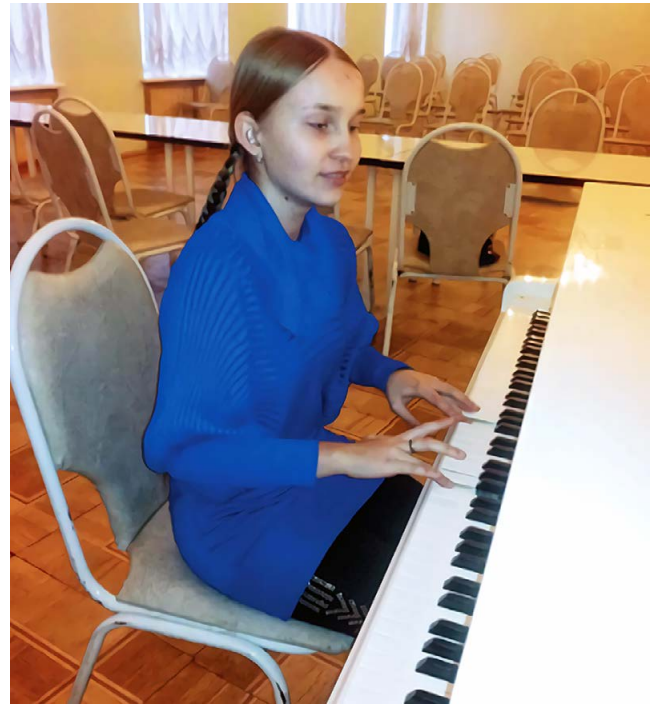
In general, what was your childhood like? Was it happy?

For sure, it was. I remember everything in details, even my infant thoughts, impressions, and rueful feelings. My relations loved me, they would give me numerous presents at all holidays, I would say, they used to indulge me. I used to spend a lot of time outside: I would play football, basketball, war, catch-up with the children without sensory challenges. I didn't think to be somehow different from them because of the hearing loss. Looking at my yard friends' lips I used to understand what they were telling me. But they didn't always understand me, and I used to find different ways to explain what I meant: once I acted as if I was making a bubble of chewing gum, made a helpless gesture with hands and looked at them inquiringly. And they understood that I was asking if they had any chewing gum.

Were you born with hearing loss or something incited first hearing challenges and then vision challenges?

I was a healthy child, when I was born. When I was a year and a half, I came down with the flu with complications and lost hearing some time later. But I still don't know exact reasons of this loss. When I had recovered, my relations didn't notice that I started hearing worse. Once, grandmother switched on the music and I danced to it. At some point the music stopped, but I continued dancing, which made grandmother confused. "Alena, stop, the music is over", she called out. But I didn't hear her. Then, the day after, grandmother

took me to the doctor, and they found out that I had completely lost hearing.



And what happened to your vision?

When I was four years old, the cross eye was determined. We would go to ophthalmologists and try to solve the problem. In the end, the doctors decided to operate the right eye, replace the crystalline lens with a new one. The relations were against the surgery, but the doctors *threatened* that I would lose vision one day. My relations conceded. In course of surgery, the retina detached and it became clear that I was losing vision...

So have you lost vision due to the surgical misadventure? If the doctors hadn't insisted, would have everything been relatively well?

I didn't agree with the doctors concerning the right eye surgery, I didn't see any point in it. Indeed, the eye could see perfectly: it could recognize the objects being both within touch and far. It seems to me, that the left eye could see worse than the right one, and at some point the left eye has completely lost vision just by itself.

Let's pass to something beautiful. To the visual perception that stays with you. What do you remember from the sighted world?

I remember absolutely everything from the childhood: blue sea, opalescing under the stream of sun, Caucasus mountains, faces of relations, friends, fellows, colour shades, rainbow... I could clearly see the objects both at close range and at the distance. At that time there was nothing particular in the visual perception of the world. But now it is of importance to know about the colour, and how a person, object, picture, etc. looks like. When people describe it to me, I make an image in my mind filling it with colours and visualize that I really see it.

What dreams do you have? Coloured, resonant? Or maybe tactile?

I always have coloured dreams. There, I am an individual without sensory challenges but I behave the same as in reality: I pay more attention to the smells, sensations, vibration. Perhaps, I got used to perceive the world in this way.

What did you like most of all in the childhood? What impressions/events?

Drawing with a pencil, colouring pictures, viewing the things happening around, going for a walk with fellows. I loved the sea very much... I was a curious and active child: I would try to get everything I could reach in order to learn what was hidden there. For example, the Caucasus mountains. I was curious of what was concealed in them and what was behind them. Standing on a balcony, I would look at them attentively for a long time. But I distinguished the regular life only: the cars passing by, the smoke billowing from the chimneys of houses, trees, swinging in the wind...

How did you appear to be in Sergiyev Posad residential care facility? Did you become a familiar face soon?

In the hospital ward, my mother was told about Sergiyev Posad orphanage for the children who are deafblind, and mother decided to send me there. In the middle of autumn, I entered the residential care facility. The principal, deputy principals, and the teacher accepted me at once. Apparently, they liked me. I missed home very much, I didn't like it in the residential care facility: the food in canteen wasn't tasty, children

seemed too strange, although the lessons appeared to be easy. I remember that at those times when I could see, I dreamed of entering the school as soon as possible, I would often go there with grand-aunt (she was a primary school teacher) and see as the children were learning how to write and read, having fun on the go, drawing, modelling, playing musical instruments, etc. I liked the atmosphere. And here... I remembered Braille and dactylology fast, but the teacher didn't understand it and would continue showing the same Braille letters and dactilemas every day. At that time, I got disappointed in my dream of going to school. Only two years after I began acquiring new knowledge in Russian, mathematics, literature.

The social environment was very uncomfortable... most children had low lexical stock, and in fact, I had nothing to talk to them about. Aiming not to lose senses because of loneliness, I would go to the teachers and second-part-of-the-day teachers and talk to them. My school life lasted for 13 years, and during three last years I eagerly waited for getting the school certificate in order to come back home and live comfortable full life.

Was it the time when you became keen on reading?

I learnt reading Braille when I was nine years old. I had nothing to do apart from the studies and pottery – only reading books. That is why a book is my interlocutor, friend, relieving from downward thoughts and stress. I read all school library: classical literature, love stories, fiction, adventures... I used to take books to the bedroom. According to the schedule, children had to go to bed at 9 p.m., but by force of my home habit I couldn't fall asleep at that time, I used to read a book or a textbook.

How were you overcoming the deafblindness?

It is a difficult question... I, being a seven years old girl, didn't perceive the vision loss anyhow. The square bandage, attached to an eyebrow with plaster, slipped off the treated eye, and I was turning my head, trying to distinguish an object or a

person's face. In front of my eyes there was thick fog having the colour of white milk. Through it, I could see nothing but a trail of light. But I didn't even think of getting upset. I decided, that I would succeed notwithstanding the vision and hearing loss.

At the beginning, I enjoyed life, didn't count the problem as a problem, wondered seeing sorrowful and tearful relations nearby... I remember, that I would try to restore past world. I would sit in a child's play armchair, press the buttons of remote control, switching on The Nutcracker, and would listen... without seeing images. Later, the understanding came, and desperation invaded me, a twelve years old girl. My outlook on life became misty and gloomy: I felt the mockery of fate and hopelessness. I suffered, and school life would add even more sufferings... I was overtaken by desperation caused by realization that no one would ever be able to give me vision back. I blamed life for taking my vision. The hearing loss didn't confuse me, I absolutely could receive new information without it – for example, reading the speech from the lips. The suicidal thinking or thought of entering the convent, aimed to insulate myself from the world, used to cross my mind...

How did you manage to stop yourself from doing that irremediable thing?

The thought of grandmother stopped me, I loved her a lot. I thought that she would suffer and feel sore a lot, and I felt shameful, I didn't want to give her pain. That is why I stopped the attempt of committing suicide...

Nonetheless, you pulled yourself out. Tell us, how it was.

Nine years after, even after graduation from school, I really tried to fix my grave psychological state. I thought of it a lot, found and solved the knots of the psychological problems, and to my amazement I saw deafblindness to be beautiful and wise...

Has your lifestyle changed after this rethinking?

Yes, it has. Alongside with reflecting I was active with all my might: I would go to classes to the college, to work to the call centre, I would go on tour with Touchable performance, attend events, meet interesting people. My view towards deafblindness brightened up, and I discovered that it wasn't a disaster, it was even a blessing. The deafblindness gave me a lot, developed good traits of character, cracked a mystery of inaccessible worlds.



You are a sociable person. What do you feel about incident acquaintances on the Web?

I feel calm and good naturedly about everyone, and I want to support everyone. Thanks to the theater I got experience in communicating to all manner of people, I can quickly find not only common ground but also the mode of communication. In social networks, I accept the friendship invitations only of those whom I know personally or by hearsay. I don't like strangers sending friendship invitations without a message. If I were them, I would write a message first...

In 2014, you carried the flag at Paralympics closing ceremony. How did it happen? What did you feel walking over the stadium?

In 2013, I went to Sochi to take part in the artistic project called Class of the World. Famous sculptors, artists, designers and fellows with disabilities, that could draw, model, create images from different materials, gathered there. We worked together, created the Park of Sculpture before the Olympics. Later, I was invited to the Paralympics and offered to take part in the Games closing ceremony. While carrying the flag, I felt millions of spectators' eyes... and my embarrassment. It was my first public appearance.

And in the end, did you like it? Did you want to continue appearing in public?

I can't say that I liked it, I was anxious, it was unusual that millions of people were looking at me. The Paralympics ambience interested me more, I wanted to feel the atmosphere of this holiday. Apart from the rehearsals at the stadium, I and the fellows went to Krasnaya Polyana, where we visited alpine events. I felt the vibration of the announcer's voice, sounded over the stadium. I also felt the voices of people, who shouted at the top of their voices, rooting for their countries. I am very sensitive to vibrations, I hardly can bear powerful ones, it feels like they hit my body and nervous system. That is why I am glad that we weren't there for a long. And at the stadium, I got acquainted with different people, it was interesting for me to get to know them.

We are now close to the appearance of Con-nection Fund. The way you see it, how

important is appearance of such non-profit organizations? What does the Fund give you?

The Fund gave me an opportunity to take part in Touchable project, travel around the towns and cities of Russia and European countries, take taxi at no charge which, by the way, wasn't my personal pleasure, but the way to avoid problems with accompaniment, to get from A to B and back independently. It is important that the Fund assists with distribution of information on deafblindness, I often act in the Fund videos, movies, and clips, filmed on this topic.

You took part in a theatrical project Touchable pretty much at the very beginning. How did you blend into the repertory company?

I remember the day when I joined the project. At the master class, the actors without sensory challenges were given the task to put on a blindfold and ear plugs. The objective was to show them how the individuals who are deafblind feel the world, how they live in their world. I came to one of the actors, touched his hand and wrote the following on his palm in block letters, "Hello". I didn't realize that he was an individual without sensory challenges, I would write on his palm patiently, put his hands on my shoulders, so he could feel and imagine what I am like. He had tried to puzzle out the letters several times until he finally understood the question, "What is your name?". Then he got used and started understanding my utterances with ease. And he answered in the same way. Later, after he had put off the blindfold and ear plugs, he told that it had been difficult to perceive the world as if he had been deafblind; his head began to ache badly because of experiment. Though, he partly seized what was it like to be an individual who is deafblind.

This is how I became confident that I can communicate with the repertory company. And further there were acquaintances, communication, friendship...

Theatre for you – what is it?

Theatre is a process of development, not an entertainment. During rehearsals, you better understand your deficiencies, how to

transform disadvantages into advantages, how to improve the skills. And the director's tasks (which are sometimes very challenging) help to overcome diffidence, inhibitedness, sadness.

In 2019, you turned to the literary creativity. What encouraged you to write?

My friend Irina Povolotskaya motivated me, she persuaded me to write a literary text. I was doubtful of my skills, didn't understand how to put thoughts into writing, how to cast aside tensions and fear of a blank page. Finally, I made several diary notes, showed one of them to Irina, she praised them and suggested to keep a blog in social networks. It inspired me, I began writing more essays, stories, and poems.

In one of the essays you wrote, that a person shall be perceived as a poet, artist, sculptor instead of being perceived as a deafblind poet, deafblind artist, deafblind sculptor. Do I get it right that deafblind prefix devaluates the things a person did?

I wanted to point out, that people often emphasize person's disability, as if their health stood in the first place, and the personality – in the second. I consider everyone to be equal to me, and that's completely irrelevant what person I get acquainted with, whether they have vision loss or hearing loss. If a person announces their challenges by themselves, I get aware of and take them into consideration in order to interact with this person in the future, accounting their needs. For example, if I communicate with an individual with vision loss, I give the object, that I want to show, into their hands, instead of handling it in front of their eyes. But basically I never ask a person about their health challenges.

You study at college, how is it there?

I am in the third year now. To be honest, I can't believe that. I feel like I entered college just a little while ago and socialized ... after the school years. Now I am in the constant flow of communication and academic activities: I attend lectures and seminars, accomplish

tasks, communicate with assistants... The main part is assistantship. Without an assistant, I wouldn't get any lecture materials, wouldn't be able to interact with a teacher.

How does it proceed? Why are intervenors so important?

I call intervenors as assistants now, because they are not teachers. An intervenor usually helps a child to study academic information, explains rules and the point of assignment, but my assistant translates lectures, delivers the words of a teacher from Skype, helps to find necessary academic information on the Internet, models reference papers and course papers, and sometimes accompanies at the events... His work is similar to the work of interpreter of dactylography. Yes, my assistant is very important for me. I, being as a foreigner without him, wouldn't make even a step on my own... A while back, I thought of employment and realized that I needed assistant's help. But there are difficulties as well. The intervenor's salary is low, and there are just few of those who want to be an assistant.

What do you dream of?

That is a complicated question... Earlier on, I dreamt of various and different things, but now I almost have no dreams. Expect perhaps of going to Brazil one day in order to look at the waterfalls, feel their power, acquire new smells and flavours...

What are your favourite smells? And flavours?

The favourite smells are of the sea, mango, almond, cool and fresh summer morning (early in the morning during summertime: fresh air, odours of grass, trees, and flowers). The flavours are of mint, raspberry, and Italian herbs.

According to you, what is the beauty of the world manifested in?

In nothing. Deafblindness is more beautiful than any other visible amenities. I just live in the world as it is.

Parents Share their Experiences

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- Smitha Chakravarthy (interpreter)

At CRESAM, we are regularly asked by grandparents, support services for parents, some schools and child care services, and also by hospitals about parenthood. Some examples of their questions are: how to be a deafblind parent nowadays? what is the pathway of parenting?

Resources are missing to meet those requests. Indeed, these are scarce publications and studies on parenthood for individuals who are deafblind in France. As a part of the Parenthood and Deafblindness project, we collaborated with Droit Pluriel (an organization for the accessibility rights of persons with disabilities), to ask two mothers' testimony of their journey and their condition.

My advice to parents in my situation would be to tell it like it is. As a parent, you always want to show your strength. Yet you are the way you are; you have weaknesses, you may have shortcomings, you can make mistakes... you are a human being.

I am married and I have 11 years old twin girls. I've been on sick leave since my disability grew: I have level 2 Usher syndrome, which makes me the one having vision and hearing loss to a great extent. I was born with this genetic disease and it made me hesitate for a long time before having children. However, I have been always pulling through. I got a degree, had a job for a long time, a house, nothing could stop me. During the pregnancy I was very anxious. I was afraid that my children would have the same syndrome. As soon as we were able to run the tests,

we found out that they didn't have it and it was a great relief.

As the children were growing up, I had to take care of them with increasingly reduced visual acuity. By the time they were in first grade, I couldn't tolerate any luminosity. We had to rethink everything. How was I going to cope? I was afraid to pick them up from school. I was afraid of how people would look at me. In the end, everything went well: the advantage of having vision loss is that I can't see what goes on around me.

I had my daughters followed by a psychologist so that they could talk freely about my disability and that it would not have any repercussions on them. As for me, I spent four months in a centre to readapt to my increasingly poor vision and to learn to use a white cane. I was in tears during

the first lesson. But in hindsight, I realize I learnt to live a new life thanks to this new independence. I can move around more easily. When I came back from the rehabilitation centre, I was in for a huge shock. I used to be in charge of running the whole house, but I didn't fit in anymore. I couldn't help the children with their homework, I couldn't cook, I felt useless. I found it hard to reprise the role of their mother; my husband and children tend to do everything for me, to foresee my actions. It is psychologically very hard when you're made to feel helpless.

Fortunately, I have a very close relationship with my daughters. I would always tell them the truth, without ever being defeatist: I always used to be a fighter. You have to find the right words for them to understand, at their own level.

Since we all love animals, I told them that I was going to get a guide dog, to help them better accept the white cane. As time goes by and as they are growing up, I feel that they can help me and that it is natural. In a broader sense, I feel that they are more aware, more open to diversity.

Céline Bauza, 44 years old

If I had any advice for parents in a similar situation, I would tell them that nothing is a taboo.

I am an individual who is deafblind, I have Usher syndrome, I'm married and have two children aged 15 and 18. My partner has hearing loss and both my children don't have any sensory challenges. For 15 years, I co-taught kindergarten children with the organization Deux Langues Pour une Education (2LPE). I had to stop working for health reasons: I started losing my vision due to Usher syndrome. Despite this, I was never told that I could not have children or that I could not work or participate in any way in social life. The urge came to me naturally, without any apprehension. I didn't feel radically different, I felt capable and confident enough to become a mother. Indeed, I was born with hearing loss caused by Usher, benefited from a bilingual education in French sign language (LSF) and was supported by very positive narratives. I have built a clear identity with which I have no inner conflict, and I have always felt very independent. Deafness is normal for me, everyone around me speaks sign language and this communication seems natural to me.

When my eldest son was born, I did not yet have any difficulties related to my vision loss. Later on, we adapted by switching to tactile sign language, especially when there

was little light. I built a strong bond with him, he understood my specificities right away. When my daughter was born, my vision had deteriorated considerably but my daughter quickly adapted. I noticed that at the age of three and a half she had already developed automatisms where I was involved. Probably because she had observed my difficulties and also those of her uncle. One evening at a school party, after the show was over, she came straight away to take me home: I hadn't said anything to her, but she had understood that I couldn't see after dark.

In general, we talk freely about everything: the special orange glasses, the white cane... I also feel it is important to inform them of the changes in my vision challenges. Unlike my hearing loss, which is not progressive, my vision is declining and I have to communicate about what I can or cannot do.

Sometimes my children speak around me and I try to make them understand that when I am present, they have to use French sign language (LSF) or tactile sign language (LST), because otherwise, I am excluded from the conversation. The most difficult thing was to help them with the homework with my degraded vision. We hired private help for this but it was difficult because we didn't have any specific financial assistance for this and the technical equipment to compensate for my visual impairment is already very expensive.

■ INTERVIEWS

I am lucky to have a lot of support. With my brother, who is deafblind and has Usher like me, we have come up with many ideas and accessibility solutions. Sometimes I need help, but that doesn't take away from the independence I have in other ways. And I have always been able to cope with my needs and those of my children. They can speak three languages: French, French sign language (LSF) and tactile sign language (LST). As a

result, during my son's internship in a shop, he was able to greet a customer who has hearing loss in sign language. My children are immersed in a multicultural environment every day, as they have both friends without sensory challenges and friends having hearing loss. This has a big influence on their open-mindedness. My dream was to have children and to have a happy home, and I am delighted that this is now the case.

Angélique Dutrinus, 43 years old

International Project Together In CHARGE

Recommendations in Education for Children with CHARGE Syndrome

Many parents of children with multiple sensory impairment sooner or later run into the same questions, “When and where can my child go to school?” and “What support is needed?”.

For some of these children regular education is possible, with or without specific support in the classroom. When an individual has complex disorders or sensory impairment, regular education often becomes more difficult.

Children with CHARGE syndrome often have multiple sensory impairments such as those related to hearing, vision, balance, and smell. In addition, they often have already been through a lot during the years before they enter school, due to the disorders associated with the syndrome. This means they often start school at a 1-0 disadvantage. Sometimes parents are even told that their child with CHARGE would not benefit from education at all!

At Royal Kentalis, we offer specialized education for children with complex sensory needs such as children with CHARGE. Relatively many children with CHARGE syndrome visit our schools. They are offered specialized education, often with an individually tailored program. Our experience is that most children with CHARGE syndrome develop very well on many domains when offered the right

support in education and communication.

Throughout the years, a lot of expertise in teaching pupils with CHARGE has been gained.

The question on how to design education for children with CHARGE syndrome optimally is, however, also a recurring question. The learning potential and well-being of children with CHARGE syndrome is often under pressure because of the medical and sensory consequences of the disorder. Sensory impairments, difficulties in processing information from the senses, and physical discomforts have their impact on, for example, communication, self-regulation, and social interaction. As a result, children with CHARGE syndrome are at risk for under- and overstimulation and under- and overestimation due to varying functioning in different circumstances.

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PROJECT IN
COLLABORATION
BETWEEN ROYAL
KENTALIS (THE
NETHERLANDS)
AND STIFTUNG
ST. FRANZISKUS,
(GERMANY)

Unity in Diversity

There are large differences in functioning between children with CHARGE. However, due to the problems with gaining, processing, and integrating information from the senses, many children with CHARGE do have similar support needs. Within the schools of

Kentalis, we felt the need to map out what exactly these support needs are. To increase knowledge and insights in this specific area within the Netherlands, we got the opportunity to do an international project.

Project

With the support of a European subsidy (Erasmus Plus), a project was started by Kentalis in collaboration with the German organization Stiftung St. Franziskus in Heiligenbronn. This organization offers (similar to Kentalis) education and outpatient services to students with CHARGE syndrome (among others).

The goal of the exchange project was to strengthen the knowledge about CHARGE syndrome and to make it more explicit and more widely available. This was carried out in order to improve the quality of education for students diagnosed with CHARGE syndrome.

The project questions included the following:

- What knowledge do Kentalis teachers and educational professionals have about the support needs of their students with CHARGE syndrome?

- What do parents say about key points in the education of their child with CHARGE syndrome?
- In what ways do German teachers and education professionals consider supporting needs of their students with CHARGE syndrome?
- What is described in literature about support needs of pupils with CHARGE syndrome?
- What recommendations can be made for improving the quality of education for students with CHARGE syndrome?

On the one hand, the project consisted of retrieving the already available knowledge about the support needs of learners with CHARGE syndrome within Kentalis. We did this by administering questionnaires to parents and teachers. In addition, there were two visiting weeks to the Stiftung St. Franziskus in Germany.

Project in Short

We started with a literature study and paid special attention to the thesis of Gail Deuce, PhD. Based on the literature study and the input from the questionnaires from parents and teachers, we designed an observation form that was used during 2 exchange weeks at the Stiftung St. Franziskus in Germany. Cases were also discussed with colleagues

from the ambulant service and Prof. Dr. Andrea Wanka, expert in CHARGE syndrome.

The observation form contains 7 domains: sensory attunement, social-emotional, communication, conceptual skills/executive functioning, use of routines and structure, time and space, learning conditions, orientation and mobility.

Recommendations for Use in Practice

The result of the project is a manual that describes recommendations for each domain to be used in practice.

Regarding **sensory attunement**, being aware of the impact of the multisensory impairment is very important. Children expend a lot of energy in taking in and processing

information. Children with CHARGE syndrome often seek for specific postures, or pressure and movements that explicitly give them more information about the position of their bodies. This requires recognition, understanding, tolerance, and support from professionals in education.

With regard to the **social-emotional** domain, the most important result is that it is so important to discuss the difference between what a student masters in or can, and what the student can handle in certain circumstances. This is an important distinction to prevent from overestimation/overstimulation and underestimation/understimulation.

For students with CHARGE syndrome, dealing with their own emotions and empathizing with others can be very difficult. These students need to obtain clarity and tailored support. For example, visual, explicit support for social situations through naming positive behavior and offering alternative activities can be helpful.



In the **communication domain**, it was found that most students used a variety of forms of communication, including gestures, speech, concrete (tactile) materials, pictures, drawings, and images. Visual and tactile support and repetition are important. Also, learning from real experiences (instead of information from books, pictures, language) is very important in education. The more real experiences are, the better they are for learning!

The **conceptual skills/executive functioning** domain is about cognitive processes to achieve your goals and to deal with changing demands or situations. Many students with CHARGE syndrome experience difficulties in this area and need support in this area. They often benefit from clear frameworks, structure, visual or tactile support, examples and imitation, repetition, reducing complexity (from much to little help) and learning to organize new and familiar tasks or activities.

With regard to **routines and structure, time and place**, the importance of strategies for being able to work independently and make transitions by themselves is mentioned. Routines, familiar sequences, and visual support in the program could provide clarity. Here, one-on-one time for teaching is important to be able to provide explanations and adapt to the needs of a specific student.

Regarding **learning conditions**, it's indicated that customized adjustments are needed. They depend on the individual needs of a student, such as adapted furniture or a low-stimulus environment. Other learning conditions are smaller classes and adjustment of educational program to what a student can handle at any given time.

Orientation and mobility addresses motor development delays. Students have a particular way of walking or moving around, associated with lack of the balance organ and often low muscle tone. It is necessary to determine together in what body position a student can learn best, what is a supporting versus a challenging learning environment and what are the best opportunities for relaxation.

Other recommendations have been made in the area of diagnostics/assessment, further research and policies.



Kentalis Webinar

Following the project, we were eager for spreading the knowledge and experiences we gained from parents and teachers. We wanted to share this with other parents and professionals in the Netherlands.

As there was no possibility to arrange a physical meeting in 2021, we organised a

webinar. On March 31, 2021, this one-time digital meeting was held with explanations about and benefits of the project, it included interactive part with video clips, various speakers and an interview with our colleague and expert by experience, Pieter Vergeer.

Interview with Pieter Vergeer

Pieter Vergeer works within Kentalis in Zoetermeer and is an expert by experience. In an interview he told us about his search for more information about what CHARGE syndrome means for him. Asking questions about different domains we looked at within the project, he told us about his strengths and the challenges he faces in his own life. He told us, how he is searching for the balance,

what he can and cannot do at a given moment, and how he deals with all the information that comes towards him in different situations. That what he wants to do is not always possible.

However, Pieter ended his contribution with a beautiful message, **“Give and take time, for yourself and for the child with CHARGE syndrome! Look at the possibilities!”**.

More Information?

The recommendations of the project Together in CHARGE have been recorded in a manual.

If you are interested in this manual, or have other questions or remarks, please contact us by sending an email to chargeteam@kentalis.nl

Certified Deafblind Intervenor Specialists (CDBIS)

A new certification, Certified Deafblind Intervenor Specialist (CDBIS), encompasses several years of work of CNIB Deafblind Community Services, DeafBlind Ontario Services, and the Academy for Certification of Vision Rehabilitation (ACVREP).

The development of CDBIS specialists is an outcome of work of the Intervenor Services Human Resource Strategy (ISHRS) that was completed by organizations supporting individuals who are deafblind in Ontario. The deafblind

community was consulted in the development of the fundamental standards in Ontario during the ISHRS initiative. Further, individuals who are deafblind were consulted on CDBIS Certification Criteria.

What is CDBIS?

CDBIS specialists are trained professionals who work with individuals who are deafblind and those having dual sensory loss. CDBIS specialists are highly skilled in providing auditory, visual, and tactile information to someone who is deafblind. In doing so, they provide access to information and opportunities for inclusion, skill development, empowerment, and independence.

Learn More

CDBIS is based on fundamental quality standards developed in the Province of Ontario, Canada. However, the certification is open to any intervenor that meets one of

CDBIS specialists are committed to the Intervenor Organization of Ontario's *Intervenor Code of Ethics and Guidelines for Ethical Conduct*.

Certified professionals demonstrate focus on quality, 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.

four eligibility categories and passes the certification exam. Learn more on <https://www.acvrep.org/certifications/cdbis-landing>.



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Being and becoming a member of Dbl

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

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

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

Being an individual member of Dbl means

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

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

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

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

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

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

Mirko Baúr, Strategic Vice-President Dbl, Chair ComCom



Deafblind
International Dbl

DbI Communication Ambassador: Call for Action



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

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

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

What are the responsibilities of a Communication Ambassador:

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

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

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

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