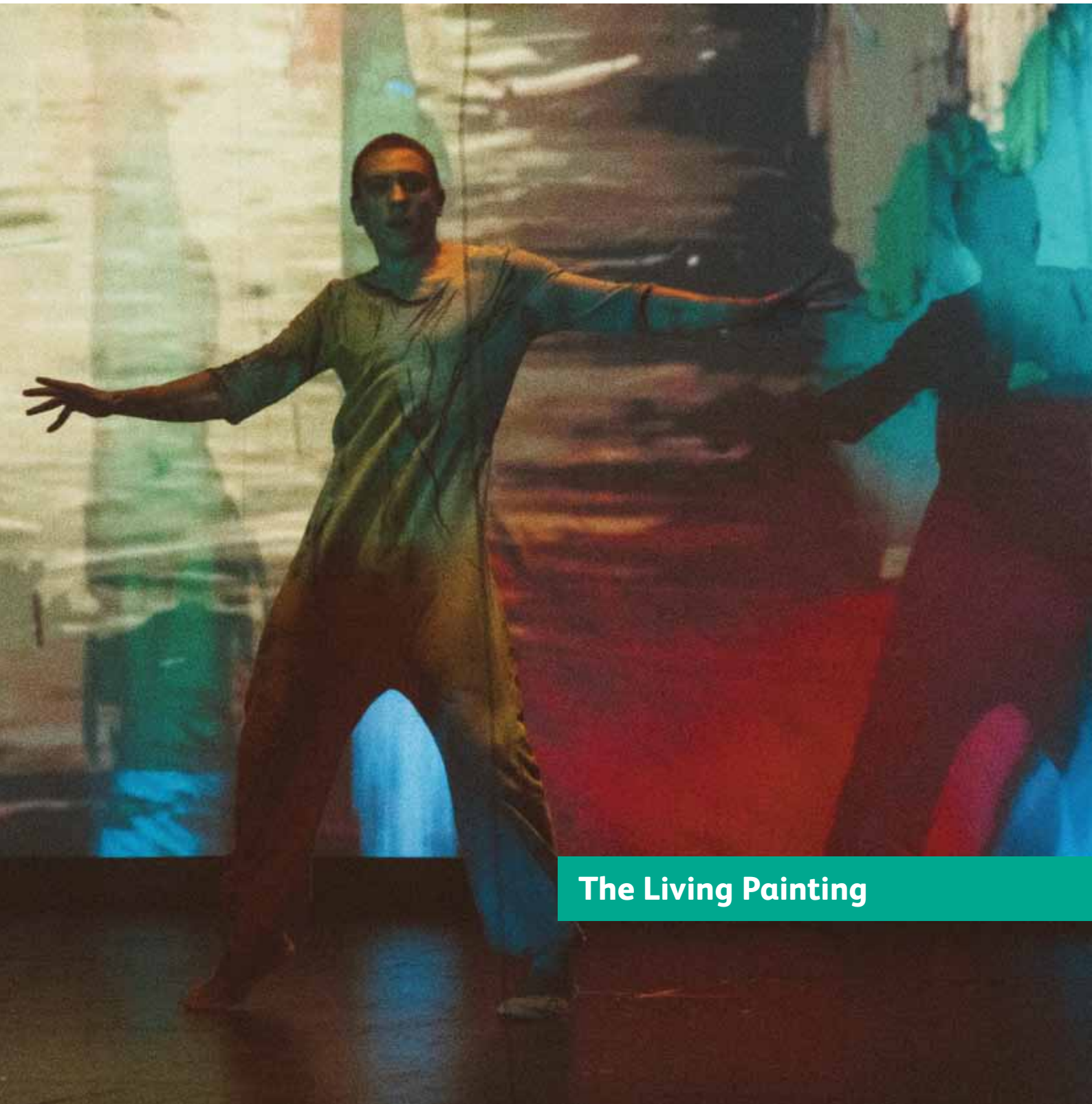


**DbI**  
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THE MAGAZINE  
OF DEAFBLIND  
INTERNATIONAL

Number 61 • July 2018

# *Review*



**The Living Painting**

Deafblind International was formerly known as the International Association for the Education of Deafblind People.

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The editor will be pleased to receive articles, news items, notices of books and information on forthcoming events, such as conferences and courses. Photographs are welcome – preferably not from digital cameras.

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Opinions expressed in articles are those of the author and should not be understood as representing the view of DbI.

DbI Review is also available on disk. If you are interested in receiving your copy in this format, please contact:

DbI Secretariat  
Able Australia, Camberwell  
Email: gary.daly@ableaustralia.org.au  
Tel: +61-8-94735451  
Facsimile: +61-8-94735499

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**Editor**  
Stan Munroe  
Email: information@deafblindinternational.org

**Design**  
Sally Coleman

**Distribution and DbI Membership**  
DbI Secretariat  
Email: secretariat@deafblindinternational.org

**DbI Website**  
Stan Munroe and Secretariat

**Editorial Office**  
CDBA Office, 2652 Morien Hwy,  
Port Morien, NS, Canada B1B 1C6

Email: information@deafblindinternational.org  
Website: www.deafblindinternational.org

Tel: +1 902-737-1453  
Fax: +1 902-737-1114

**Cover:**  
Living Paintings / Anima Chroma performed  
by Inclusion Theatre Company of Russia

## A message from the President

Dear Friends and colleagues,

I know many of you will have attended the Network of Americas conference held this past April. It was fantastic that the conference was dedicated to Professor Jan Van Dijk, definitely one of the most important and much loved people in our field.

Huge thanks must go to Perkins School for the Blind, Marianne Riggio, the scientific committee and everyone involved. Sadly, I wasn't there; it must be the first DbI conference I have missed in so many years and was sad not to have been able to attend.

I am delighted to congratulate Carolyn Monaco for being awarded the Anne Sullivan Medal for excellence in the field of deafblindness. I am equally pleased for all the other Award recipients and great to see their dedication and hard work recognised.

Generally, I haven't been travelling much but the DbI Management Committee and Board are still very much in touch and working hard. Our three priorities



of diversity, technology and knowledge remain at the heart of what we do.

We are looking forward to the WFBB conference in June and the Young Researchers conference in Russia in October. I know Able Australia and the Scientific Committee are working hard on the DbI World conference in 2019.

As ever, our huge thanks must go to Stan and CDBA for the wonderful work on this Review; Able Australia and Gary Daly for the massive amount of Secretariat work and Maria Brons who is taking forward Frank's work as treasurer. Our deafblind community is important and it's a privilege to be part of it.

**With Best Wishes**  
**Gill Morbey President**

*“Our three priorities of diversity, technology and knowledge remain at the heart of what we do.”*

## Editorial

Welcome to the 61st and Summer 2018 Edition of DbI Review.

One of DbI's key focus areas is Diversity. Without asking for articles specifically about diversity, articles keep arriving from far corners of the world to satisfy that focus. The diversity of articles is not just about originating from so many regions but also about the diverse assortment of subject matter and its ideas and programs. This edition is no exception with the diversity of material and the diversity of locations from which the papers originate.

This edition features writers with specialized articles from: Egypt, India, Denmark, Guatemala, Russia, Italy, Canada, Burkina Faso and Switzerland. In addition, several articles appear from Perkins International Latin America and the Caribbean co-written by authors from Brazil, Argentina and Mexico.

The edition begins with an article written by Amal Azzat from Cairo Egypt titled: "Advocating for the right of education for the learners with deafblindness and multiple disabilities in Egypt". Amal Azzat's determined advocacy to get the Government of Egypt to provide educational services for children with multiple disabilities is remarkable. She is truly a hero.

The article from Sense International India titled: "What Inclusion means to us", is an eye-opening expose of what inclusion in



India means for individuals with deafblindness, their parents and caregivers with respect to education, health care, employment, etc. The narratives from caregivers and parents speaks about how persons with deafblindness are denied basic human rights within Indian society. Their struggle for inclusion is an everyday struggle.

Karina Hoejbjerre Seiler has an intriguing article entitled: "Empowerment of Children with Dual Sensory Loss". She described her experience with "narrative coaching" as a means of empowering children with deafblindness to deal with their disability by focussing on their experiences, emotions and reflections about their situation, dreams, issues and future.

In addition to these feature articles, this edition follows the magazine's tradition of presenting brief updates from the following DbI Networks: CHARGE, Communication, Youth, Outdoor, Usher Syndrome, Research and from the newest network, Adapted Physical Activity Network. Have a read about Emma Boswell's train experience.

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## Vice Presidents' Messages

BERNADETTE KAPPEN REPORTS



The year has gone by so quickly for DbI. In looking back, we have achieved many of the goals that we identified. The area that has seen tremendous growth is the effort to promote diversity. Social media has helped keep us connected to activities happening around the world. So many wonderful projects are offering individuals with deafblindness more access and the ability to participate in daily life.

The recent Network of the Americas Conference brought together people from over 20

different countries. The enthusiasm of the participants and the high quality of the presentations shows the growth of DbI as well as the need for sharing information. DbI appreciates the work that the Perkins staff did to host the conference.

As we look ahead, the Scientific Planning Committee for the World Conference in 2019 is busy working on the program. The sub-committees for each of the topics: Accessibility, Communication and Technology are identifying speakers for the plenary sessions and will be reviewing the abstracts for the workshops. DbI is excited to be partnering with Able Australia and

the local Host Committee is working hard to create a memorable time while at the conference.

Individuals who are deafblind are successful because of the people who support them. In our field we have so many individuals who have made or are making outstanding contributions. On behalf of the Awards Committee, I hope you will consider nominating individuals for the Young Leadership Award, the Distinguished Service Award or the Lifetime Achievement Award. The information on how to nominate an individual is on the DbI website. DbI will present awards at the World Conference in 2019.

Bernadette M. Kappen (B.Kappen@nyise.org)

FRANK KAT REPORTS



Sometimes I wish I could slow down time; it is flying by with so much yet to do. In a year from now the current Board will look back (and forward of course) at our achievements. And that is exactly what we did during the last ManCom meeting in Hyannis, Cape Cod this past April we looked at what urgent matters were before us and what we needed to focus on going forward. I am happy to say that we are well on our way.

As an organization we are very active on aspects of Diversity and Accessibility; although admittedly both these items need to become an increased part of our collective organizations' institutional behaviour. So, this matter will certainly be on the agenda of DbI for some time.

I'm very happy with the articles that appear in DbI Review. There

could be more 'personal stories' produced so we can share them on social media. Talking about social media, the new-look website is working well and our Facebook membership is growing weekly. However, we still need to make further improvements to increase the visits to the website. We are already working on this and request that if any of you have any ideas and if you want to help us, please let us know.

The Networks are working well. Trees Schrauwen van Nunen has agreed take on the coordinator role at least until August 2019. At the world conference in Australia next year there will be extra time provided in the program for all the networks. Graciela Ferioli, a member of the Scientific Committee, has assured us she will take care of that.

At the beginning of this year I handed over my role as a DbI Treasurer to the experienced hands

of Maria Brons and Trees Schrauwen van Nunen, both from Kentalis. Earlier in February and March I collaborated with Hans Rijvers (also of Kentalis) and our Auditor for our yearly audit check, to see if our income is spent accordingly to what we agreed upon. I need to report that I'm still smiling and can report that DbI is doing fine and is still financially healthy. Due to new software and some major changes in the DbI's administration (positions of Treasurer and the Secretariat), I can report that DbI will be able to work in line with the new European Union Privacy Regulations (GDPR – General Data Protection Regulations). We will inform all the members in person later this year.

The last thing I would like to share is an upcoming special conference for young researchers planned for Moscow in early October. You can read about it on our website and facebook site, or check the official conference website: <http://so-edinenie.org/conf-youth/en>

Frank Kat (Frank.kat@versatel.nl or Frank.Kat@outlook.com)

## Advocating for the Right of Education for the Learners with Deafblindness and Multiple Disabilities in Egypt

Amal Ezzat

I graduated from the Psychology Department of Ain Shams University<sup>1</sup> in 1993 and eventually worked as a psychologist in a hospital for mental health. In 1995 I participated in a training course at the University's faculty of medicine to study speech therapy and worked at Ain Shams Hospital as a speech therapist for 30 months. I was fortunate because I trained with the greatest professors at the faculty of medicine at Ain Shams hospital at that time.

### The challenge of deafblindness

The biggest challenge I faced in my work was in the year 2000 when I worked as a speech therapist in a center for children with cerebral palsy. I was working with a child with deafblindness and multiple disabilities. For the first time I felt like a failure due to my inability to communicate with the child. I became frustrated and started to search for information about deafblindness. I was surprised to discover that there was not any school or organization in Egypt that taught those children. But I did not wait a long time to find my way in the field of deafblindness. Luckily, in 2002, I read an advertisement about a training course on deafblind education in Egypt. It was a cooperative effort between Oslo University and Egypt. This course was the first step on my journey to

understanding deafblindness. From that time I became fascinated by working with children with deafblindness and multiple disabilities. The Norwegian experts taught the Scandinavian method in deafblind education. They emphasized the development of social interaction as a basis for development of communicative expressions.

### Lack of resources about deafblindness in Arabic language

The second challenge I met was the lack of information and resources about this disability in the Arabic language. I found only two books and a chapter in a book about deafblindness in the Arabic language. This problem motivated me to introduce the first research in the Arabic language about deafblindness, at a conference at the University of Banha<sup>2</sup> in 2007. I also



translated into Arabic booklets titled "Co-creating Communication"<sup>3</sup> by Anna Nafstad and Inger Rodbroe, and other articles about deafblindness and the Callier Azusa scale.<sup>4</sup> In addition, I finished my thesis for a Master's Degree in 2010 which was the first such thesis about deafblindness in the Arabic language in Egypt. This opened the door for more studies in the field of deafblindness. With

<sup>1</sup> [www.asu.edu.eg](http://www.asu.edu.eg)

<sup>2</sup> University of Banha

<sup>3</sup> These booklets were produced by DbI's Communication Network

<sup>4</sup> The Callier-Azusa Scale designed to aid in the assessment of deaf-blind and multihandicapped children in the areas of motor development, <https://www.utdallas.edu/calliercenter/evaluation-and-treatment/azusa-scale>

my colleagues we started to introduce lectures and training courses to train teachers and parents about the principals of deafblind education. I should note that the number of studies in deafblindness in Egypt as well as deafblindness awareness has increased since that time.

### The magic of social interaction

I am very passionate about the Van Dijk approach<sup>5</sup> as well as the booklets “Co-creating Communication”. They highlight the role of social interaction in communication development. Social interaction works like magic in improving communication with children with deafblindness and multiple disabilities. It is the cornerstone for the development of the child. The child’s motivation to communicate emerges from the positive experiences through togetherness. Many researches confirm that when the child securely attaches to their caregiver, he/she has a secure base which provides the motivation to explore their world around them helping them to develop communication.

### What is after social interaction?

The question I always wondered about was what follows social interaction? Will we continue to play with the children or do we teach them like their peers? How do we encourage them to get out of their comfort zone to face the real life?

These questions motivated me to read more about deafblind and multiple disabilities education and eventually enrolled in training courses online from Perkins School for the Blind. I was very impressed with Perkins and I dreamed someday of participating in their Educational Leadership Program (ELP). I was eventually accepted to take this course beginning in 2014. While I was happy to achieve this dream at the same time it was another challenge to leave my three children in Egypt to be away in the USA for such a long period.

### Advocating for the right of education

After working with children with deafblindness and multiple disabilities and their families now for eight years, I was surprised that the law

here in Egypt prohibits any child with more than one disability from attending school. I could not imagine that we could deprive any child of his or her right to an education. I discovered that the lives of all those children are tied one way or another to legislation. So, I suggested to the families that we needed to take the initiative to meet the Egyptian Ministry of Education officials to advocate for these children’s right to education.

The families of deafblind and multiply disabled children chose me to represent them in discussions with Ministry officials. We started our way in advocacy in 2010 when I went to the Ministry of Education to convince the officials about this issue. I showed them some pictures of the children in various activities and explained how we communicate with them and emphasized the need to train teachers and open classes for these individuals. While these officials were convinced about this issue, they indicated that they needed to take this proposal to the Education Minister. It was three years before anything developed. I happened to meet the Minister at a conference and asked him why the Ministry of Education prevents children with deafblindness and multiple disabilities from their rights to an education. The Minister promised to try to find a solution for those children.

After one week the Minister invited me and several specialists in special education to meet to discuss the project for deafblind and multiple

disabilities education. This was the happiest day of my life because we had won the first round. Finally, we were able to move forward the right for these children in Egypt to get an education.

I had established the Hope City Foundation (HCF) in 2014 as the first step towards implementing this project. But not too fast there were delays. The Minister was changed along with other officials in the Ministry. With every change I had to convince the new officials to continue in the project. Some were convinced; others did not care. At this time, I received the acceptance to travel on a scholarship to Perkins for the ELP course.

### More Inspiration

While at Perkins School for the Blind in Boston, USA I was inspired by the story of John Dix Fisher<sup>6</sup> when he went to Paris to discuss the idea about the Perkins School. I wished I would have been able to deliver the same idea in Egypt and start a school model for students with deafblindness and multiple disabilities.

It was at Perkins that I found the answers for all



*“We are doing our best to ensure that every child in Egypt has their right to a free and appropriate public education in locations close to his/her home.”*

the questions I was thinking about “what is after social interaction?”. I knew that we should prepare these multiply disabled children for transition from childhood to adulthood to allow them to be productive members in their community. Without a doubt, they should have equal opportunities to work, live and love.

I learned new strategies in teaching children with these disabilities. I was so happy to find the missing link in their education that I was looking for. When I returned to Egypt in 2015; I started in the Hope City Foundation a small school model similar to the Perkins model.

### The influence of advocacy

In the Hope City Foundation (HCF) we believe that education is the key to all for sustainable development. We are doing our best to ensure that every child in Egypt has their right to a free and appropriate public education in locations close to his/her home.

In 2015 we presented an initiative called “Your Right to Learn” to the Egyptian

Ministry of Education, recommending that four classes were required for children with dual sensory impairment and multiple disabilities. The Minister approved this!

In August 2016, we trained 14 teachers from the Ministry of Education in Hope City Foundation, about the strategies for teaching learners with deafblindness or multiple disabilities and visual impairment. The training consisted of 60 hours of theoretical training followed by 72 hours of practical training. We also prepared the first curriculum for teacher training in Egypt which was approved by the Ministry of Education. We also opened the door between the Ministry of education and Perkins School for the Blind to train teachers through the curriculum of Perkins International. In addition, we encouraged teachers to study in the Perkins Educational Leadership Program to increase the number of qualified teachers.

Our advocacy work continues to influence the government and NGO’s in

*“Social interaction works like magic in improving communication with children with deafblindness and multiple disabilities.”*

<sup>5</sup> www.perkinselearning.org/dr-jan-van-dijk-child-guided-assessment

<sup>6</sup> John Dix Fisher first considered the idea of a school for blind children based upon his visits to Paris at the National Institute for the Blind and was inspired to create such a school in Boston. [https://en.wikipedia.org/wiki/Perkins\\_School\\_for\\_the\\_Blind](https://en.wikipedia.org/wiki/Perkins_School_for_the_Blind)



Egypt to open more classes and train more teachers for this disability. As a result, in 2018 Perkins trained 30 Egyptian teachers from the Ministry of Education in the Perkins Academy Curriculum.<sup>7</sup> We are so proud to see our initiative succeed and grow larger; encouraging others to work for this same cause. It encourages us to continue to work hard for the rights of these children as we haven't reached the end goal yet.

When we believe in our dream, we will do our best to achieve it!

For more information, contact Amal Ezzat (amalezzat@yahoo.com), Speech and Language Pathologist/Special Education Consultant, Hope City Foundation (<https://b-m.facebook.com/Hope-City-Foundation-HCF>)

<sup>7</sup> www.perkins.org/international/academy

**Editor's note:**

a) Two weeks before the teacher training was to begin in August 2016, the author was diagnosed with cancer, which she suggested was the biggest challenge in her life and testing her courage. She proceeded with the 15-day training program despite her physician's advice. The author said: I discovered that I am strong and needed to complete my dream and fight my health later. I decided to give the training to the teachers at its designated

time, since I want to ensure these children have their rights to an education". After the training program she had the surgery then went to Boston for follow up chemotherapy and radiation. b) The author attended the Network of the Americas Conference and had a workshop presentation titled: Developing Early Language Skills of Children with Deafblindness and Multiple Disabilities through Social Play.

**EDITOR'S MESSAGE** (continued from page 3)

Once again, the Country Reports feature interesting submissions from: Burkina Faso, Canada, Egypt, Switzerland, Germany and Russia. They are all a great read.

Conferences continue to be an integral activity of DbI. The First Network of the Americas Conference, hosted by Perkins School for the Blind, held in Hyannis (Cape Cod, USA) this past April was an outstanding success, as indicated by the summary article outlining the conference's activities.

By publication time, we will be just weeks away from the First Young Researchers Conference scheduled for Moscow Russia in early October 2018. Also, we are just a year away from the 17th World DbI Conference hosted by Able Australia and located in Gold Coast Australia.

In closing, I want to extend my deep thanks again to the many collaborators who submit articles to support this valuable publication.

Respectively,  
Stan Munroe,  
July 2018

# What Inclusion Means to Us?

## Parents' and Caregivers' Perspectives in the Indian Context

**Ms. Smriti Dhingra**  
Manager Research  
Sense International India

**Mr. Deepak Krishna Sharma**  
Assistant Manager, Networks  
Sense International India



"Inclusion refers to the opportunity for persons with disabilities to participate fully in all the educational, employment, consumer, recreational, community and domestic activities that typify everyday society." (Tilstone & Rose, 2003)

**Introduction**

In general, there exists different views of how an inclusive society functions and has room for diversity. Inclusion in India is not specifically defined in the recent Rights of Persons with Disabilities (RPWD) Act, 2016<sup>1</sup>. However, the principles of United Nations Conventions on the Rights of Persons with Disabilities (UNCRPD)<sup>2</sup> supports inclusion in the areas of education; skill development and employment; social security; health rehabilitation and recreation.

The idea of inclusion continues in society because the meaning of it has been significantly framed in various international, national and local level contexts. Sense International India<sup>3</sup>, in its desire to understand the perspectives of parents of Persons with Deafblindness (PwDb) with respect to 'Inclusion', conducted a small session with thirty-five parents and caregivers from twenty-two states of India. This session was conducted during a National Meeting for Parents and Educators of persons with deafblindness (PwDb) and Adults

with Deafblindness (AwDb), where the objective was to understand the idea of inclusion in various settings and what it means for them. This article highlights the discussions during that session, where parents felt that inclusion means to them: education, employment, participation in society, health and rehabilitation services.

**Inclusion in Education**

WHO and the World Bank's *World report on Disability* (2011)<sup>4</sup> writes "if children with disabilities (CwD) are denied the opportunity to participate, then it will lead to isolation, decreased autonomy and lower quality of life. UNICEF's 'The state of the world's children 2013: Children with disabilities'<sup>5</sup> writes, "Education is the gateway to full participation in society". These two international organizations focus upon education as the primary concern where inclusion of CwD is highly important. Similar views were expressed during this session by the parents and caregivers of PwDb, about the need for inclusion primarily at elementary and secondary school levels and

secondarily during higher education.

Article 45 of the Constitution of India<sup>6</sup> directs the state to provide free and compulsory education to all children up to the age of 14 years. One of Article 45's major provisions reflecting the true essence of inclusion for CwD is outlined in Section 3 signifying the Right of Children to Free and



Discussions with parents during session

<sup>1</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5419007>

<sup>2</sup> <https://www.un.org/.../disabilities/convention-on-the-rights-of-persons-with-disabilities...>

<sup>3</sup> [www.senseintindia.org/](http://www.senseintindia.org/)

<sup>4</sup> [www.who.int/disabilities/world\\_report/2011/report.pdf](http://www.who.int/disabilities/world_report/2011/report.pdf)

<sup>5</sup> <https://www.unicef.org/sowc2013/>

Compulsory Education Act (RTE-2009). This was later amended in 2012<sup>7</sup> to include Children with Special Needs (CwSN).

The experience of parents of PwDb paints quite a different picture. When these parents approached their local schools, they were denied admission explaining that because of the students' disability, teachers were not ready to take responsibility for them. These individuals were considered a burden for a regular classroom setting due to lack of trained human resources and school infrastructure. Further, teachers suggested the children should be enrolled in special schools or a resource centres run under Sarva Shiksha Abhiyan (SSA)<sup>8</sup> i.e Education for All, a Government of India initiative. It is important to note that these resource centres are located far from their residences

For higher education, government mandates three percent of positions reserved for students with disabilities (SwD) in government institutions. According to the National Centre for Promotion of Employment of Disabled People (NCPEDP) in its 2015 survey on 'Status of Disability in Higher Education'<sup>9</sup>, "only 0.56 percent seats are occupied in over 150 higher education institutions across the country." This clearly draws an image that SwD tend to drop out during their initial level of education, a similar concern shared by the parents of PwDb. Parents believe that deafblindness, being a complex disability and not identified in the census, lacks proper awareness. This leads to poor accessibility to educational services and technological advancements

limiting the ability of PwDb to achieve a higher education.

To the best of Sense International India's knowledge, only ten persons with deafblindness in India have attained or are currently pursuing graduate level or higher education. This scenario reflects the status of higher education for PwDb and their exclusion from mainstream education institutions. The parents feel that the education system is functionally non-inclusive, resulting in CwDb dropping out sometime during their elementary education period. As a result, the system is only preparing these students for vocational training only, limiting their opportunity towards earning a livelihood for themselves. The parents expressed a strong need to lobby to make educational institutions and their curriculum inclusive for PwDb.

This discussion resulted in the initiation of a research project titled: 'Inclusive Education for Students with Deafblindness' under the direction of Sarva Shiksha



Teachers in a group activity discussion during sensitization training on deafblindness for school teachers, Gujarat

Abhiyan. This research project has as its objectives: preparation of an inclusive education plan, capacity building and awareness workshops for school teachers and other stakeholders in the government schools of Gujarat and Jharkhand.

### Inclusion in Employment

Employment was another area of concern where parents felt PwDb are excluded. According to parents and caregivers, inclusion also means employment and the reality is that the employment sector is not inclusive for PwDb. The RPWD Act, 2016 provides that four percent of positions in government jobs be reserved for PwDs, which includes one percent of employment for persons with multiple disabilities including PwDb.

Also, private sector employers are provided incentives by the government to employ PwDs. It is observed that the job requirements for employing a PwD is quite specific; employers expect these candidates to have these usable

skills. For example, a candidate must be able to multi-task, travel without any inhibitions and have computer software related skills. Employers are often not keen to invest in facilities and technology which would make the office environment accessible and disability friendly. In such cases, the person either loses the job opportunity or if employed, doesn't receive enough opportunities to grow while in an inaccessible work environment. This situation only qualifies exceptional PwD's or persons with a single disability to attain employment. In these situations, the PwDb are left behind as they require extra support for communication and accessibility in the work setting.

Another concern is when PwDb's drop out of school without attaining a higher education. Their only feasible opportunity is now vocational training and self-employment. Vocational Rehabilitation Centres, now known as National Career Service Centres for Differently Aabled (NCSCDA)<sup>10</sup>, have been established to provide vocational training to PwDs. It has been observed by parents and the Sense International India team members that the job skill provisions are not modernised as per market demands. These job trades are only made available with adaptation for persons with a single disability (a person with visual impairment or with a hearing impairment), thus excluding PwDb from these opportunities.

Recently as the market for vocationally trained youth with or without disabilities has expanded, the Ministry of Labour and Employment has made provisions for jobs through the National Career Service Portal (NCSCP)<sup>11</sup> for youth with or without a disability. This portal has opened the job



Mr. Parag Namdeo, Head Advocacy & Networks Development, Sense International India in a meeting with Vocational Rehabilitation Centre official

market where employers prefer to recruit a person without disability or having a single disability and able to multi-task with efficiency, quickly learn skills and not demand a specialised work environment. This again has resulted in exclusion of PwDb from employment. As the last resort, parents now are exploring self-employment avenues, which requires investment and capacity building for the family of the PwDb.

To address the need for vocational training and self-employment, Sense International India team brought synergy to the NCSCDA ecosystem through awareness and capacity building for professionals associated with vocational rehabilitation for the employment needs of PwDb. As a result, three AwDb persons are now receiving vocational training in Kolkata and Patna.

Sense International India has also focussed on self-employment where they created the capacity for PwDb to be involved in various trades. They have provided 83 AwDb persons with financial support to set up their own Income Generation Activity (IGA) to earn their livelihood.

### Inclusion in Health and Rehabilitation Services

Article 47 of the Indian Constitution<sup>12</sup> explains the mandate to improve nutrition and provide for a public health system. While various flagship health policies/programmes were initiated, there was no access to services for PwDs. This has now been changed with the adoption of the National Health Policy's 12th Five Year Plan which has provided an inclusive approach towards healthcare.

Despite these provisions, parents of CwDb still face challenges and discrimination in accessing the health care system. For example, discriminatory and insensitive remarks are made by medical professionals about a child's disability. Often treatment is not provided to PwDb specific to their needs because they lack understanding about communicating with them. This insensitive approach towards the PwDb does not only exclude them from health services but further causes their overall discrimination in the society.

<sup>6</sup> <https://indiankanoon.org/doc/1791268>

<sup>7</sup> [mhrd.gov.in](http://mhrd.gov.in) School Education

<sup>8</sup> Sarva Shiksha Abhiyan (English: Education for All Movement), or SSA, is an Indian Government programme aimed at the universalisation of elementary education "in a time bound manner", as mandated by the 86th Amendment to the Constitution of India making free and compulsory education to children between the ages of 6 to 14 (estimated to be 205 million children in 2001) a fundamental right.

Retrieved from [https://en.wikipedia.org/wiki/Sarva\\_Shiksha\\_Abhiyan](https://en.wikipedia.org/wiki/Sarva_Shiksha_Abhiyan)

<sup>9</sup> [www.ncpedp.org/Education](http://www.ncpedp.org/Education)

<sup>10</sup> [mynacareers.com/tag/national-careers-service-centre-for-differently-abled/](http://mynacareers.com/tag/national-careers-service-centre-for-differently-abled/)

<sup>11</sup> <https://www.ncs.gov.in/>

<sup>12</sup> <https://indiankanoon.org/doc/1551554/>





John, adult with deafblindness at his canteen at National Association for the Blind, Delhi. The canteen was initiated through income generation support provided by Sense International India

Another serious concern which parents emphasized was intrusion into their privacy while accessing these services. In one incident, an AwDb person accompanied by her parent to the hospital for a medical check-up, the doctor did not request the parent to step out or seek consent from AwDb person to allow their parent to stay. Experiences like these portray the approach of medical institutions where PwDb are not consulted as they are often considered to be childlike. The concept of consent and dissemination of information and communication is often neglected in health institutions.

In another conversation, it was observed that PwDb are not informed about their sexual and reproductive health. There exists a notion where PwD are not considered sexual beings; as a result, the information about their own body and sexual and reproductive health is not shared with them. This leads to a situation where decisions about their health are taken on their behalf without any consent and communication.

Understanding this neglected situation, Sense International India started organizing training sessions to provide a comprehensive sexual and reproductive health education program. These trainings conducted with AwDb highlighted a huge gap in exclusion for PwDb in the area of sexual and reproductive health.

Sense International India has improved the knowledge capacity for 99 AwDb by providing information about body and body processes and other information about sexual and reproductive health. Before these trainings were initiated, the parents and caregivers were first questioned about the need for these trainings as well as the content. There was initial reluctance to send their children for these trainings. Often when they attended the trainings with their children, they did not properly communicate the information to them. Eventually this changed after training. Parents observed that their children were better understanding their bodily changes and becoming more confident about managing their body independently, requiring less support. As a result, there was a greater demand for similar training.

Regarding health care for this disabled population, there exists a range of accessibility barriers. These include: lack of awareness about their location; the healthcare infrastructure likely may be inaccessible; personal assistance would likely be unavailable; the services unaffordable; and especially a dearth of professionals who understand deafblindness and the ways to communicate with them. Other examples to highlight the inaccessibility of health and health products for PwDb include the lack of availability of such products as: sanitary napkins; condoms and other contraceptives; pregnancy test kits; medications, etc. Furthermore, every time these individuals may need to access these products, they generally need

to seek the support of another person, which increases their dependency as well as intruding into their privacy.

The lack of rehabilitation services is also a source of worry for this population, as well as the availability and quality of technical aids and appliances. Sometimes the aids and appliances they receive are unsuitable or do not function. PwDb's demand a system where they could receive customized devices at an affordable cost with trained professionals available to provide support and counselling.

These experiences described by PwDb individuals themselves, stress the need for inclusion in health and rehabilitation services. A mechanism must be developed where services are made available in reasonable time and health professionals are trained to be more aware of people with these disabilities.

### Inclusion in Society – Holistic Approach

Parents and caregivers associated with Sense India belongs to different cultures and class systems. Expectations for their inclusion in society will only be fulfilled through systemic and policy changes. A change in society, through a holistic approach, is required where provisions are made such that no PwDb is left behind in their engagement with society.

During the exchange of thoughts about exclusion from society, parents explained how their children are being excluded from the playground, even family ceremonies in their own family settings, including their children's birthday parties. They understand that inclusion in the society and other services is their children's constitutional right, but as they shared their stories, they underlined the harsh truths of the society in which they live. They furthermore demanded attitudinal change

in every aspect. While these experiences painted a heart-wrenching picture for us at Sense International India, it reinforced our resolve that we are all responsible for making society a better place to live for everyone.

The following are a few comments made by parents demonstrating the lack of inclusion:

- Parent from Madhya Pradesh, "People stare at my daughter whenever she goes to play in the park".
- Parent from New Delhi, "Swings in the play areas are not made accessible as per the child's need hence I cannot leave my child alone".
- Parent from Jharkhand, "Nobody showed up to my son's birthday party from the neighbourhood".
- Parent from Orissa, "Parents from the neighbourhood think that my child will harm their children, therefore, they instruct their children not to play with my child. My only question is: don't other children fight with each other during play?"
- Parent from Mumbai, "During family ceremonies, I am indirectly asked not to bring my child along because she is deafblind."

- Parent from West Bengal, "I had never thought about my son's marriage. One day he expressed the desire to get married but my extended family vehemently opposed the idea.

### Conclusion

These narratives of caregivers and parents speaks about how PwDb are denied basic human rights in our present society. This struggle for inclusion is an everyday struggle where intervention in policies and an attitudinal change in Indian society is necessary. Yes, there are systemic changes where current government Acts and Policies have increased opportunities in various sectors and services for PwDb's; but at the same time it is very important to observe how many of these reserved seats are actually occupied by these individuals. These discussions not only represent the systemic gap but also highlight the reality of our non-inclusive attitudes. The change cannot be brought by taking a micro to macro level approach or vice-versa. The approach must be both ways together because we are already many decades behind in bringing systemic and attitudinal changes in comparison to other developmental concerns.



Adults with Deafblindness in a body mapping activity during a training on 'Sex-Education for adults with deafblindness' by Sense International India team

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All photographs by Sense International India

# Empowerment of Children with Dual Sensory Loss

Karina Hoejbjerre Seiler, Consultant for children with deafblindness, Centre for Deafblindness and Hearing Loss, Aalborg, Denmark<sup>1</sup>



Throughout my working life I have been concerned about just how creative a consulting conversation with a child could be, for it to be as meaningful as possible. Inspired by narrative coaching, my perspective has recently become focused on empowering their living conditions and externalizing challenging problems. I found that my counselling can be even more applicable and effective, if I focus on the child's experiences, emotions and reflections on their reality, dreams, issues and future...

The Centre for Deafblindness and Hearing Loss provides national counselling for children, families, pedagogic staff, social workers, habilitation workers and educational facilities for children (0–18 years of age) with acquired and congenital deafblindness.

I am a consultant for a group of children and youngsters, primarily those with acquired deafblindness, living in the area of the Danish capital Copenhagen. Given the fact that my task is to guide these children to live meaningful and acceptable lives despite their sensory loss, I constantly try to improve my approach in each case.

Previously I have been very focused on supporting each individual primarily by using various technical aids and asking such questions

as: “how are you doing right now?”; “how can I, or someone else, help you”? Generally, my approach for each child is first to estimate their degree of hearing and vision loss, then suggest various solutions to the family members, teachers etc., based on my assessment of each individual's situation.

Inspired by a course in narrative coaching<sup>2</sup> (based on systems theory) I decided to change my way of counselling by doing something different. I started trying methods and techniques inspired from narrative coaching... using examples such as externalization and outside witness methods. My question guide was inspired from Karl Tomms' externalizing circle-questions<sup>3</sup>. Instead of asking, “Is physical education/ gymnastics difficult? Why?”, I would try to open up my

line of questions and ask; “what are the challenges with physical ed/gymnastics? What do these challenges do to trouble you? How do manage to get through anyway? These strengths – can you bring them with you into your other areas in life, where you will meet other challenges?” After a period of time, I realized that the center of my counselling should focus on: how each child should empower themselves to cope with the lifelong consequences of their dual sensory loss and help them appreciate that the person is not the problem but their disability is and they must learn to cope.

The latest research from Swedish Scientist Moa Wahlqvist<sup>4</sup> about people living with Usher syndrome has shown that children and young adults living with dual sensory loss are highly

designated to deal with psychiatric issues later in their adult lives.

Based on her interviews with young adults living with dual sensory loss (and supported by information from experienced colleagues), she suggested that the reason for the many psychiatric challenges these individuals face, have their foundation in childhood. Therefore, it is a priority to focus on the child – to support them to cope as a person with deafblindness. As pedagogic consultants, my colleagues and I follow each child closely throughout their development. We need to be aware of the importance of empowering these children by guiding them to develop personal coping strategies that provide them with a clear understanding of their complicated situation.

In Denmark we have a saying; “It is easier said than

done”! Respectfully to the fact that there is no other expert than the children themselves, I do have a proposition. When a consultant is allowed into the child's personal thoughts about coping with their life, we need to use conversational narratives to assure each child they are important and strong. Externalizing their dual sensory loss should hopefully make it more acceptable for them to live with their condition, although it was not their choice. This would provide the child the opportunity to blame their sensory loss on “that bad guy that makes their life difficult while at the same time believing: “I am creative, athletic, happy, strong, moody, compassionate, etc.”

As the consultant, I try to emphasize the inner strengths that appear in our conversations. I want the child to think; “my

personality is not my condition or my sensory loss”. These conversations allow me to ask questions like: “How do you feel about Usher syndrome?

How much is the Usher bothering you today when going to the movies with friends?” etc. These conversations also help to reassure the child's inherent strengths and allows them to understand and deal with their lifetime sensory losses. Consequently, the individual should be better able to handle difficult changes throughout their lives whether it be going to an unknown place, moving to a new home, starting education, changing jobs, etc. Practicing small changes with success, will provide the child an opportunity to gain inner strength for dealing with larger changes throughout their life.



<sup>1</sup> The Centre for Deafblindness and Hearing Loss ([www.cdh.rn.dk](http://www.cdh.rn.dk)) is a small corporate member of DbI

<sup>2</sup> Narrative Coaching allows one to uncover, understand, and change what truly drives human behavior through the process of listening to and understanding. ([narrativecoach.com/program](http://narrativecoach.com/program))

<sup>3</sup> Karl Tomm 1992, Canadian psychiatrist & family systems therapist.

<sup>4</sup> [https://www.researchgate.net/profile/Moa\\_Wahlqvist](https://www.researchgate.net/profile/Moa_Wahlqvist)



*“In using the narrative and systems theory of thinking, my aim is to capture the essence of each child’s concerns.”*

In using the narrative and systems theory of thinking, my aim is to capture the essence of each child’s concerns. Actually, I create a drawing as a summary of our conversation. Each drawing serves as an ‘outsider witness’<sup>5</sup> of what the child’s finds important which I then document in my working journal. My aim is to co-create the drawing with the child during the conversation that we have, whether it is at their home or at school.

Recently my colleagues and I have started a teen-group for 4 girls with different levels of dual sensory loss. Our goal is to facilitate a process for the girls to draw something important together – to visualize and externalize difficult issues or useful aspects of their lives. Examples include “who/which things are our helpers, and who/which things are troubling”.

Listening to each other is an important key in narrative conversation. Danish

philosopher Ole Fogh Kirkeby<sup>6</sup> says; “I only understand what I say, when I hear it from others”. In Danish we have the ‘effect of the mirror’, meaning that I know myself better in meaningful connections and relations to significant others.

Members of our teen-group will be witnesses to important thoughts and emotional expressions from each other, and hopefully they will understand themselves better, and be better able to cope, using their inner resources, with life’s changes.

The points of the individual drawings will become significant in future counselling with the child’s parents, teachers, pedagogic staff etc., since they provide

this network information on exactly what makes sense for the child! What could be more important...?

Much more work needs to be done. I hope to meet European and International colleagues for co-creating workshops & conferences to share information and experiences about; how to be more significant as a guest in the lives of people living with dual sensory loss.

**For more information, contact Karina Hoejbjerg Seiler by email at: k.seiler@rn.dk**

*“Much more work needs to be done. I hope to meet European and International colleagues for co-creating workshops & conferences to share information and experiences about; how to be more significant as a guest in the lives of people living with dual sensory loss.”*

<sup>5</sup> Michael White (1948–2008). Article, (in Danish), *Narrativ praksis* 2006.

<sup>6</sup> Danish philosopher, Ole Fogh Kirkeby (1947)

## Overview of the First DbI Network of the Americas Conference

The inaugural conference of the recently formed DbI Network of the Americas was a resounding success.

The event with the theme ‘Partnerships for Lifetime Learning’, drew over 400 people from 23 different countries over the period April 15–18, 2018. The conference was hosted by the Perkins School for the Blind and Deafblind International in Hyannis, Massachusetts (USA). This was the second DbI conference held in the USA (the first being in New York in 1984) and first international deafblindness conference held in the USA since 1996.

The Conference chair was Marianne Riggio of Perkins International and she was assisted in developing the program by professionals and family organizers from the USA, Canada and Brazil.

### The Conference Opening

featured welcome addresses from: Marianne Riggio (Conference Chair); Dave Power (President and CEO of Perkins School for the Blind); Bernadette Kappen (DbI Vice

President); Clara Berg (President National Family Association for Deaf-Blind) and Jo Ann McCann (US Dept of Education).

A few brief examples of opening statements included:

- From Marianne Riggio, Conference Chair and Director of Perkins International’s Educational Leadership Program (ELP): “None of us do anything in isolation, whether we’re working with a child, whether we’re communicating among families, whether we’re trying to change policies, we’re doing it all as partners.”
- From Dave Power, Perkins CEO, highlighted the power of global partnerships like ELP and Perkins International Academy, a teacher training program designed to help governments around the world meet their commitments to

the United Nations’ Sustainable Development Goals (SDGs). One of the targets under the SDGs calls for an inclusive, quality education for all children – including those with disabilities – by 2030. “We know every child can learn,” said Power. “It’s our responsibility to make sure every government, community and school has the training, tools and expertise to deliver that education.”

The conference opening included a special tribute to one of the giants in the field of deafblindness, Dr. Jan van Dijk, who passed away in January of 2018. The conference was dedicated to Dr. Van Dijk. Dr. van Dijk was well known internationally to professionals in the field as well as a host of family members with whom he had great rapport and influence. He was indeed sorely missed at this event and it was understood that his influence was strongly felt in the conference program.



Conference Opening and Welcome by Marianne Riggio



Plenary presenter Ed Bosso



Plenary presenter Maurice Belote

The Keynote Speaker of the Conference was Dr. Anthony Lake, Past Executive Director of UNICEF. In his presentation titled "Its About Ability: From Inspiration to "Of Course", Dr. Lake urged leaders in the deafblind community to advocate for lasting change by influencing not only lawmakers but citizens as well. "Our progress will depend upon legal and regulatory reform – and translating that reform into everyday practical action," he said. "But also, and perhaps more difficult, it will require changing public attitudes around the world."

**Plenary Sessions**

The conference featured three Plenary Sessions with the following themes: Family Partnerships; To be Included – What does it Mean? and Measuring Success. Each Plenary session included a plenary speaker followed by a plenary panel discussion.

The Three Plenary Speakers were: Ed Bosso (Perkins Superintendent), George Stern (Vice President,

DeafBlind Citizens in Action) and Maurice Belote (Project Coordinator for California Deafblind Services). The titles of their presentations were as follows: "Simplicity: The Other Side of Complexity" (Ed Bosso); "The Inclusive Mindset" (George Stern), and "Happiness and the Search for the Essence of Success" (Maurice Belote.)

The titles of the three associated plenary panel sessions were in the same order: Perspectives on Family Partnerships; Perspectives on Inclusion and Perspectives on Success.

**Workshops, Poster Sessions and Focus Groups**

Over the four-day program, over 90 workshop sessions were organized, 11 posters were displayed, and 3 focus group discussions were held.

**Reflections and Future Directions**

The daily events of the conference concluded with the final topic: Reflections and Future Direction,

featuring Robbie Blaha and Chris Russell. Robbie, a long-standing expert in deafblindness from the Texas School for the Blind and Visually Impaired, reflected on the conference and deafblind services in the USA; while Chris represented the new blood in deafblind services and spoke about what he viewed as the future direction for services in the USA.

**Conference Closing**

The conference concluded with the evening Awards Banquet featuring an address from

Ambassador Aubrey Webson (formerly from Perkins School for the Blind), titled: Leaving No Child Behind.

Perkins handed out their prestigious Ann Sullivan Macy award to several individuals; while DbI presented awards for Distinguished Service and Life Time Achievement in the field of deafblindness.

Prepared by Stan Munroe



# The 1st International Young Researchers Conference on Deafblindness

is a new and big event for most talented students, graduate students and young scientists from Europe, Asia, America and Russia who are interested in problem of visual and hearing impairments.



**THE MAIN GOAL OF THE CONFERENCE is the exchange of experience between young specialists in deafblindness and the creation of an international network on which depends the future of the science and practical assistance to persons with deafblindness.**

**TIME AND PLACE**  
Moscow on 9–11th of October

**Services FREE for participants**

- Registration fee
- Coffee breaks, lunches, welcome cocktail, farewell banquet
- Night Moscow city-tour

**Conditions**

- We invite young specialists (at the age up to 35 years) already having experience of scientific and practical work, as well as students who are just starting their way in the field of studying deafblindness.
- We are waiting for the presentation of big and small researches and practical reports in the field of physiology, medicine, social work, psychology and education.
- Possible forms of participation: without presentation, presentation – master class (20 minutes), short message (5 minutes), poster presentation.

**Registration**

- The registration fee is not required for participation.
- During the conference the participants will be provided with free food (coffee break, lunch, welcome cocktail, farewell banquet).
- Registration is available on the website <http://so-edinenie.org/conf-youth/en/>
- For more information, please, contact the organizers [j.mayorova@so-edinenie.org](mailto:j.mayorova@so-edinenie.org)
- Travel-coordinator (hotels, visa support) [k.yaritskaya@so-edinenie.org](mailto:k.yaritskaya@so-edinenie.org)

**Organizers:** The Russian Deafblind Support Foundation "Con-nection" ([www.so-edinenie.org](http://www.so-edinenie.org))



## ABLE AUSTRALIA WELCOMES THE WORLD TO THE GOLD COAST FOR THE 17th World Conference on Deafblindness

August 12–16, 2019

Hosted by Able Australia<sup>1</sup> the 17th Deafblind International World Conference 2019 will be held on the Gold Coast, Queensland Australia<sup>2</sup>, August 12–16, 2019. The conference will take place at the Surfers Paradise Marriott Resort & Spa<sup>3</sup>. The Scientific Committee<sup>4</sup> has selected as the conference theme: “Sharing the Knowledge to ACT: Accessibility. Communication. Technology. Now is your time to ACT!” Each day of the conference will feature one of these three themes (ACT).

To commemorate this conference, the logo design includes the acronym ACT in black and white font,

with the words ‘Accessibility, Communication and Technology’ in smaller font at the bottom. The boomerang represents Australia and acknowledges Able Australia, the host organization.

Conference attendees, including individuals who are deafblind, families, academics and professionals are encouraged to attend the conference. A variety of perspectives including research and best practices in deafblindness within the themes will be shared throughout the conference period. The period of Early Bird Registration will be December 01, 2018 through February 28, 2019.

<sup>1</sup> www.ableaustralia.org.au

<sup>2</sup> https://www.destinationgoldcoast.com

<sup>3</sup> www.marriott.com

<sup>4</sup> The Conference planning committee includes representatives from Australia, Argentina, Canada, Denmark, India, Japan and USA

### CALL FOR PAPERS NOW OPEN

Call for papers open until August 31, 2018.

17th Deafblind International World Conference  
www.dbiaustralia2019.com.au

The Scientific Committee is seeking presentations that align with the conference theme: Accessibility, Communication and Technology.

All applicants interested in presenting at the conference should prepare their presentations to meet accessibility requirements for a fully inclusive experience for all participants.

**For further information, please contact:**

Roxanna Spruyt-Rocks, Scientific Committee Chair at  
dbi2019info@deafblindontario.com

The Scientific Committee will confirm presenters in early December 2018.

#### CONFERENCE INFORMATION

www.dbiaustralia2019.com.au

**Conference dates:** 12 – 16 August 2019

**Registrations open:** 1 December 2018 – 28 February 2019

**Dbi network workshops/meetings:** 11 August 2019

**Venue:** Surfers Paradise Marriot Resort & Spa  
158 Ferny Ave, Surfers Paradise QLD 4217

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## Education Beyond a Thorn-Ridden Path

Burkina Faso

**B**ambara Olivia is 11 years old. She was born deaf in Garango in the East-Central region of Burkina Faso. When she was 7, she suffered a trauma in the eye, this trauma left a scar in the cornea. She had now become visually impaired as well, leaving her deafblind.

At that time her parents and people around her thought that she would not benefit from going to school. She was kept at home.

Olivia comes from a low-income family where her father is a farmer and her mother a housewife. She is the second born of four children. Her family's financial circumstances and her disability meant that her parents came to the conclusion that Olivia would not benefit from going to school and that they could not afford to send her to a special school. This situation is not unusual in Burkina Faso. Many children with disabilities are not supported to go to school by their families or communities. Not all teachers are aware of the country's policy for all children to have equitable access to education. This situation is changing; more teachers are being trained in inclusive education. However, life was hard for Olivia living with deafblindness in her rural community.

She was often left alone at home with very little communication between her and her family. There seemed to be no way to change her situation. The other children of her age were not very interested in her because of

her deafblindness. She was seen as different. She was marginalized, unhappy, and was seen as a burden on her parents because she was not independent. She was totally reliant on others to support her every day existence.

In 2013 a community-based inclusive development (CBID) team came across Olivia in Garango. This programme is an implementation partner for CBM's Inclusive Education project. After her identification she was referred for eye health care. During medical examination by an ophthalmologist, the corneal scar in the one eye was found to be irreparable. The second eye was diagnosed as having low vision, so she could use this vision to find her way around and to learn in school.

Her hearing was also assessed. She was diagnosed with a sensorineural hearing loss, leaving her profoundly deaf. No amplification aids were available. She and her family were provided with lessons in signed communication.

Despite the support of the CBID team with eye medicines, her parents were still pessimistic and reluctant to send her to school. The CBID team worked hard to convince Olivia's parents to send her to school. Following these discussions Olivia was enrolled in the Bougla Ladenbourg School in Galindo. This is a state school supported by, amongst others, Centre Saint Martin e.V. (Germany), who has supported inclusive education activities at the school for several years.



The staff at the Bougla Ladenbourg School are trained in Inclusive Education techniques. All children are used to seeing and being in class with children having different needs and strengths. They are used to diversity. The inclusive ethos of the school means that signed communication is accepted as an important way for communicating with children who are deaf. Since Olivia's admission to primary school, her life has changed for the better. Schooling with deaf and hearing children has been positive for her. She can communicate in sign language with her classmates and her teacher.

Olivia is now in the CP2 Class (second year of primary school). She does find some aspects of school learning challenging due to the years





### Burkina Faso continued

she spent out of school, but her class teacher is supportive and ensures that she is provided with support to learn alongside her peers and to recognise her strengths. He provides her with individual lessons to help reinforce some information she may have missed using a variety of methods e.g. providing visual clues, providing concrete objects and tactile materials. As a result of this she is now a more fulfilled and self-sufficient girl.

For now, she will continue her studies in the primary school. Her ultimate ambition is to own a weaving shop where she can make loincloths to earn a living for herself. She will need to learn these skills in a training centre when she completes her primary schooling. Her parents are now very proud of her achievements and feel much more positive about Olivia attending school. She now has friends and life is more fulfilling for her. Thanks to her teacher, her CBID support, her friends in school and her parents she has a vision for her future.

Originally written in French by Valerie Ouedraogo and translated by Sian Tesni (Sian.Tesni@cbm.org), Senior Advisor for Education Technical Unit CBM International



## The Development of a Deafblind Team: A Collaborative Partnership to Meet Complex Student Needs<sup>1</sup>

Surrey School District<sup>2</sup> has developed a unique approach to support their population of students with deafblindness, one that is contingent on the collaboration of a diverse group of professionals.

Surrey School District is located in British Columbia (BC), Canada. It is the largest school district in the province with more than 70,000 students, and is extremely diverse. Surrey is currently home to 13 students, kindergarten through grade 12, who are identified as deafblind. They are very different with respect to age, strengths, and needs, as well as where they live within the district.

A key support for students who are deafblind in BC is the Provincial Outreach Program for Students with Deafblindness (POPDB)<sup>3</sup>. POPDB has teacher consultants that support students and their school districts all around the province. For the past 12 years, Surrey has had one primary consultant – Michele Kohut-Jones. Prior to establishment of the team, there were frequent changes with respect to school district partners, school-based staff and district leadership. Every

year Kohut-Jones had to effectively “start over”; a huge frustration considering that she was not even an employee of Surrey District!

The district recognized the need for a cohesive educational program, however, each team member was very different and had a limited understanding of each other’s roles. At the same time, key people were often missing from the planning table, and documentation systems were virtually non-existent. Independent Educational Plans (IEPs) were written with no understanding of deafblindness and contained goals that were unrealistic. Perhaps central to the issue, the individuals responsible for developing educational programs were ill-equipped to create meaningful materials such as calendar systems.

During September 2014 Director of Instruction Michelle Schmidt adopted the portfolios for students who are D/deaf or hearing impaired and blind/visually impaired. Soon after, Schmidt realized that educational programs were not being developed from the perspective of dual sensory impairment. With this in mind, a proposal was submitted to the Board of Education to attend the

*“The development of the Deafblind Team in Surrey School District has been a dynamic process and every variation will experience success as long as the students who are deafblind are kept at the centre.”*

### Canada

Deafblind International Conference in Romania during May 2015.

Consequently, Schmidt returned home with an intense desire to do more and with a better sense of the possibilities. Specifically, Schmidt thought to create a Deafblind team, to develop consistency and to utilize the expertise of POPDB to build district capacity.

A key role in the team would be an Integration Support Teacher with a special focus on Deafblindness. Tanya Margison was offered the then part-time position in fall 2015 and eventually becoming the case manager for all the students who were deafblind. Under Kohut-Jones Tanya learned about the unique needs of students

with deafblindness. Now a full-time position, Margison plays a huge role as the case manager, in addition to conducting assessments, supporting the classroom teacher and school team, modeling interventions, facilitating transitions, organizing itinerant supports and community outings, and being the first contact point for parents, school staff, and members of outside agencies.

In fall of 2015 there was another role specifically designated for the deafblind students, that of the District Deafblind Intervenor. Rachel Kavanagh received her Deafblind Intervenor training at George Brown College<sup>4</sup> in Toronto, Ontario. Kavanagh’s role is multi-faceted requiring a flexible approach in

supporting the educational assistants (EA) and school teams, working and building relationships with students, documenting in various forms, and making materials established by the team. It is a unique role in the deafblind world and it continues to evolve as the team and student needs evolve.

In addition to the above members, the primary team currently includes a Teacher of the Deaf and Hard of Hearing (Annie Lehbauer), a Teacher of students with visual impairments (Kendra Anderson), and, a Speech and Language Pathologist with a specialization in Alternative and Augmentative Communication (Ann-Maree Foxe). Two physiotherapists and two occupational



**FIGURE 1**  
Interaction of the Deafblind Team Legend:

- TDHH – Teacher of Deaf and Hard of Hearing
- TVI – Teacher of Blind/Visually Impaired
- OT – Occupational Therapist
- PT – Physical Therapist
- AACSLP – Augmentative Communication Speech and Language Pathologist
- POPDB – Provincial Outreach Program for Deafblind
- District Intervenor

<sup>1</sup> This article was presented at the First Network of the Americas Conference, April 2016, 2018

<sup>2</sup> <https://www.surreyschools.ca>

<sup>3</sup> [popdb.sd38.bc.ca/](http://popdb.sd38.bc.ca/)

<sup>4</sup> <https://www.georgebrown.ca/c108-2018-2019/>



Canada  
continued

therapists are also part of the team. Additional professionals join each student's team as needed, such as nursing support.

Overall the benefits have been far reaching, for students, school teams, families and team members themselves. Some of the projects we've been able to work on include: providing deafblind simulations, creating brochures, developing a literacy program, and piloting an assessment with the Provincial Resource Centre for the Visually Impaired (PRCVI) using the Transdisciplinary Play-Based Assessment<sup>5</sup> and Jan van Dijk's domains<sup>6</sup>.

Team members have been able to network outside of Surrey District at conferences and professional development days. The district has been



Pictured left to right: Kendra Anderson, Tanya Margison, Michelle Schmidt, Michele Kohut-Jones, Annie Lehbauer, and Rachel Kavanagh

supportive of staff who want Braille and American Sign Language training, as well as taking courses through POPDB who offers a Deafblind Intervention Certificate Program. These are all in addition to the many meetings and day-to-day support that the team provides.

The Deafblind team takes an inclusive, student centred, strength-based, holistic approach that recognizes diversity, as well as the need for collaboration, mutual respect, equal participation, accountability, and continuity. Team members benefit as we work smarter, not harder. The team creates a sense of community, reducing feelings of isolation as well as providing opportunities for reflective practice. Collectively there is an increase in professionals' knowledge and skills, and together we have a greater appreciation of student strengths and capacities.

The benefits to students are multi-dimensional. As student needs, wants, and cultural context are acknowledged, it impacts the supports that they receive. Goals reflect each students' uniqueness, and learning demonstrates that students feel understood. When there is increased capacity at the school level among those who work with the students on a daily basis, the students are more comfortable. We have also noted that parents have become much more involved with decision making and as a result, what we do at school more easily transfers to home.

In everything, there are always challenges and growing pains to overcome. All professionals have had to adjust their styles to allow for a more team focused approach. We have had to learn a balance between respecting where our professions differ and trusting each other in those areas of overlap. Efficient communication is another challenge as we all visit the students during the week, and often have notes or updates that need to be shared. To date, we shift between sending emails, phoning, and creating running documents on our district portal. Another challenge that we have had to adjust to is that of answering a question from the school which may require consultation with the team first. The benefits of the team far outweigh the challenges – which are almost entirely related to interpersonal relationships between the professionals. An insignificant inconvenience, when we witness the direct benefits to the students, their families, and all of those who work together to support them.

The development of the Deafblind Team in Surrey School District has been a dynamic process and every variation will experience success as long as the students who are deafblind are kept at the centre.

**For additional information, contact Michelle Schmidt PhD, Director of Instruction, Surrey School District (schimdt\_m@surreyschools.com)**

<sup>5</sup> products.brookespublishing.com

<sup>6</sup> www.perkinselearning.org/dr-jan-van-dijk-child-guided-assessment

Canada  
continued

## Dual sensory loss in older Canadians: First insights from the Canadian Longitudinal Study of Aging

Anni Hämäläinen, Paul Mick, M. Kathleen Pichora-Fuller, Walter Wittich

With life expectancy steadily increasing and the baby boomer generation reaching retirement age, the number of senior citizens is on the rise<sup>1</sup>. One consequence of this increase is that more people find themselves adjusting to newly acquired sensory challenges in their advanced years, as both vision and hearing tend to decline with age. As a result, acquired dual sensory loss is becoming an increasingly important public health concern and a research priority.

The consequences of combined vision and hearing impairments range from minor reductions in ability to perform everyday activities to major challenges participating in social activities, and even an increased risk of depression and dementia<sup>2</sup>. People with mild visual or hearing loss can often compensate for an impairment in one sense by relying more on information acquired via the other sense. They may also need to harness more of their brain capacity to interpret the visual or auditory information that comes from the world to their brains. However, when both senses have deteriorated, or cognitive function declines simultaneously (e.g., due to dementia or mild cognitive impairment), the ability to compensate for sensory loss plummets. As a result, many studies have found that dual sensory loss (loss of both



M. Kathleen Pichora-Fuller

vision and hearing function) can have much more severe consequences for quality of life and independence than either hearing or vision alone<sup>3,4</sup> and hearing impairment as average pure-tone air conduction threshold greater than 25 dB (500–4000 Hz, better ear).

For society to prepare to accommodate and care for older adults with dual sensory loss (and often many other co-occurring chronic health concerns), it is critical that we determine just how many people are at risk for or currently suffer from dual sensory loss, and whether there are modifiable lifestyle risk factors that could be addressed to prevent or slow the progression of dual sensory loss in older adults.

Epidemiologists can identify factors that could influence the risk of progression of dual sensory loss by collecting information on sensory function as well as details on various aspects of lifestyle and health in large numbers of



Walter Wittich

people. Statistical methods are then used to determine which of those factors differ between people who have developed dual sensory loss and those who have not. We are examining dual sensory loss in 30,000 Canadians aged 45–85 years, who are participating in the comprehensive, ongoing Canadian Longitudinal Study of Aging (CLSA, <https://www.clsa-elcv.ca/>). This study is the largest undertaking in Canada to understand biological, psychological and social aspects of aging. The first wave of data collection was completed in year 2015, and the study is set to run for a total of 20 years. In addition to answering numerous questions about their background, lifestyle, environment and health, study participants complete a number of cognitive tasks and undergo vision and hearing testing. Our aim is to use data from the CLSA to examine longitudinal changes in hearing, vision, health, and many other aspects of aging

Canada  
continued

as new waves of data become available. The result of this thorough examination will be a set of multidimensional snapshots of the participants' lives taken every three years. With the same data collected over time for such a large number of people, patterns begin to emerge that link dual sensory loss with aspects of lifestyle and health.

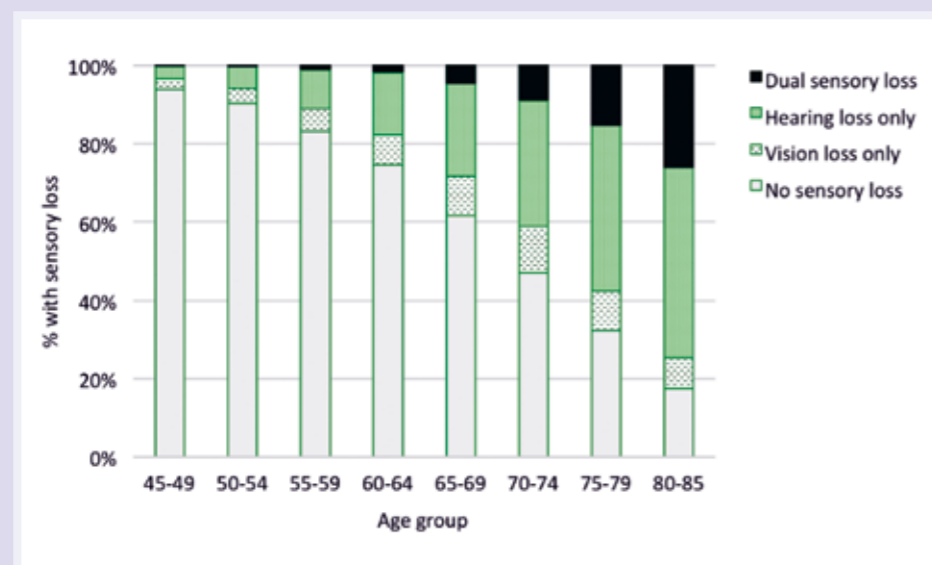
Scaling up from the data set for the 30,000 people who are participating in the CLSA, we have estimated that there are currently upwards of 130,000 older people in Canada who have measurable dual sensory loss. We define dual sensory loss here as an unaided pure-tone average >25dB HL in the better-hearing ear (for frequencies of 1000, 2000, 3000 and 4000 Hz), and pinhole-corrected visual acuity of logMAR >0.2 in the better-seeing eye (equivalent to visual acuity >20/32 (feet) or 6/10 (meters) for a Snellen fraction when measuring vision on a letter chart; i.e.

**“Scaling up from the data set for the 30,000 people who are participating in the CLSA, we have estimated that there are currently upwards of 130,000 older people in Canada who have measurable dual sensory loss.”**

the person being tested can see at a distance of 20 feet or 6 meters what a normally sighted person can see at 32 feet distance or 10 meters).

As predicted, we found that dual sensory loss was more common in older participants<sup>5</sup>: a diagnosis of both hearing and vision loss increased from less than 1% in the 45–49 year-age group to 24% in the 80–85 year-group (Figure 1). However, when we asked participants to evaluate their own vision and hearing ability (from “excellent” to “poor”), only

about 1% of the youngest age group (45–49 years old) and 3% of the oldest age group (80–85 years old) reported that their vision and hearing were “fair” or “poor”<sup>5</sup>. Thus, even though almost a quarter of this oldest age group were found to have dual sensory loss based on audiometry and visual acuity tests, fewer older people reported having sensory problems. This suggests that unless the impairments have noticeably severe consequences on people’s lives, most do not self-report dual sensory impairment that may be detected using tests of hearing and vision. This finding is important because other health problems may be worsened or complicated by sensory impairment even if the person does not notice a problem with their sensory function. For example, our preliminary results suggest worse cognitive function (executive function and short-term memory) in participants with dual sensory loss than in those with only hearing or vision loss or no sensory impairment. Strikingly, objectively measured sensory



**FIGURE 1:** Age-specific proportions of people with hearing, vision, and dual sensory loss in participants of the Canadian Longitudinal Study of Aging, based on audiometry and visual acuity measures.

loss (using audiometry and vision acuity tests) is a substantially better predictor of cognitive decline than self-reported sensory loss.

It is obvious from our results that sensory impairments and other chronic health issues are far from universal conditions in the older adults. Some women and men maintain excellent sensory function until old age. In examining factors other than age, we found that dual sensory loss was more common in men than women, in groups with a lower education and income level, and in people reporting lifestyle risk factors such as smoking, obesity, and unhealthy nutritional habits, as well as in those with diabetes or cardiovascular disease<sup>6</sup>. The significance of these lifestyle risk factors suggests a possibility that age-related dual sensory impairment could be attenuated or even prevented with lifestyle adjustments. Encouraging people to adopt healthier habits also aligns with best practices for lowering the risk of heart disease, diabetes, and dementia among other aging-associated diseases. Thus, strategies that may reduce the risk of hearing and vision loss fit well in a more general approach to promote overall healthy aging.

**“Thus, strategies that may reduce the risk of hearing and vision loss fit well in a more general approach to promote overall healthy aging.”**

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**For more information, contact [anni.hamalainen@umontreal.ca](mailto:anni.hamalainen@umontreal.ca)**

**Authors: Anni Hämäläinen and Walter Wittich<sup>1</sup> are affiliated with the School of Optometry, University of Montreal; Paul Mick is affiliated with the Faculty of Medicine, University of British Columbia and M. Kathleen Pichora-Fuller is affiliated with the Department of Psychology, University of Toronto.**

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Canada  
continued

<sup>1</sup> Walter Wittich is Leader of the DbI Research Network.



Egypt

## Education of Learners with Deafblindness and Multiple Disabilities at Hope City Foundation, Egypt

### Education= Life

Hope City Foundation is a non-profit organization established in 2014. We provide comprehensive educational services for persons from birth to adulthood with visual or hearing impairment with or without additional disabilities, deafblindness and those with multiple disabilities. We provide technical assistance and trainings for teachers, specialists, researchers and families.

#### MISSION:

Achieving quality of life, independence, inclusion and social participation for persons with deafblindness, visual impairment or hearing impairment with or without additional disabilities and those with multiple disabilities.

#### VISION:

Enable persons with these disabilities to obtain their right to appropriate education and provide them with the quality educational and rehabilitation services to achieve their independence, employment, production and participation effectively in society.

Hope City Foundation provides comprehensive educational services to children and youth with

sensory disabilities (with or without additional disabilities) from birth to 22 years old. Every child has an individual Educational program using the calendar system to recognize their schedule. Our Program offers several curriculum options using Montessori Method frameworks, including practical life, sensory life, language, math, science, social studies and art. We have four classes as follows:

#### 1. Early Intervention

For babies from birth to four years old. We invite parents to attend with their baby to learn all about their child. In this stage we help our children to explore and discover through social play.

In addition, we focus on social interaction and play, sensory development, self-help, language and communication, physical and motor skills.

#### 2. Preschool

For children ages four through eight. We focus on behavior management, self-care skills such as toileting, eating, washing and dressing, sensory integration, motor skills, cognitive skills, early language and communication.

#### 3. Early Academic

For children ages from six to twelve. We focus on development of social and behavior skills, independent living skills, communication and language, cognitive skills, early academic skills, physical

education, religion, music, art, and play skills.

#### 4. Vocational

For youth from twelve through to young adults up to twenty-two. We incorporate expanded core curriculum areas to encourage our students to be independent; preparing them to find a job to become productive members in the community. We focus on functional academic skills, daily living skills, language and communication, food preparation, manufacturing of accessories and hand-made carpets, packing, housekeeping, shopping, arts and crafts, orientation and mobility, and music.

#### EDUCATIONAL SYSTEMS

Hope City provides quality educational services for children and young adults with multiple disabilities, visual impairment, hearing impairment or deafblindness (MD/DB) through several systems:

#### School model system

(Full day): educational services are offered through individual and group sessions. It has been created as a school model to prepare the learners to easily move into

regular classes and get them used to the regular daily school system.

**Individual sessions:** Many individual sessions are offered for children who cannot attend the full-day program. The sessions are offered in several areas: speech therapy, academic skills, occupational therapy, auditory verbal therapy, visual habilitation, Braille, Sign Language, orientation & mobility, Physical Education, Art & crafts, Music, Vocational Habilitation, computer and technology.

#### Assessment department:

Assessment services are provided in the area of psychological assessment, developmental assessment, communication & language assessment, academic skills assessment, OT assessment, behavioral assessment, functional visual assessment, functional auditory assessment, assistive technology assessment.

#### Training and Consulting

**Department:** The aim of this department is to provide consultation and support to families through family training and community based

rehabilitation programs. The plan is to increase the number of high quality specialists in the field of Deafblindness/ multi-disability education.

#### The Department of Research and Scientific Cooperation:

This department is concerned with the undertaking of scientific research initiatives that contribute to the development of educational and rehabilitation services. Staff will participate in local and international conferences, assist researchers by providing human resources, organizing conferences, cooperating with local & international institutions and universities.

#### COMMUNITY SERVICE

- Hope City is doing its best to ensure that every child in Egypt has the right of quality education. We struggled to enable Learners with DB/MD to get their right in education through the initiative "Your right to learn"
- We introduced the first training course in Egypt for teachers of the Ministry of Education
- We prepared the first Egyptian curriculum to train the teachers in education for students with DB/MD.

Egypt continued



Egypt  
continued

It was approved by the Professional Academy of Teachers in the Ministry of Education.

- In 2017, the Foundation participated with the Arab Council for Childhood and Development in the preparation of the conceptual framework for assistive technology to include Arabic children with disabilities in education.

## RESEARCH AND PRESENTATIONS

Hope City Foundation (HCF) is interested in scientific research to raise awareness and improve the educational services for persons with DB/MD. HCF has undertaken several research programs and made presentations at scientific conferences. In April 2018, HCF participated in the DbI Network of Americas conference, Hyannis Massachusetts, USA, with a presentation entitled "Developing early language skills of children with deafblindness and multiple disabilities through social play". The relationship between social interaction, attention and early language skills has been identified.

The research addressed the importance of starting with developing the feeling of security with the child to develop language. The child first needs to have a secure basis for exploring the world. The research clarified that motivation emerges from positive experiences with togetherness. The communication partner should begin with the child's preference to co-create communication. The partner must observe the child's natural expressions and respond to them as if they are expressing communication. This research confirms that social play helps the child to express his emotion, improve his skills and hence his quality of life.

In July 2016 we made a presentation at the Seventh Scientific Conference of the Faculty of Education, Banha University, Egypt. The title of the presentation was "Adaptation and modification of the Montessori method<sup>1</sup> for children with special challenges, autism, cerebral palsy, dual and multiple disabilities".

In November 2016 we participated in the First

Conference of the Hearing and Speech Institute, Cairo, Egypt<sup>2</sup>, with a presentation entitled "Auditory training for deafblind children with Cochlear Implants".

We are also interested in assistive technology. We made a presentation titled "Using iPads to create communication opportunities for children with cortical visual impairment" at the 5th National Congress of the Egyptian Society of Phoniatics and Logopedics<sup>3</sup>, Faculty of Medicine, Mansoura university, Egypt, March 2015.

In addition, we participated by a presentation titled "Language development in children with autism spectrum disorder and visual impairment" in the 4th Annual National Congress of the Egyptian Society of Phoniatics and Logopedics, Faculty of Medicine, Ain Shams university, Cairo, Egypt, March 2014.

**For more information, contact Amal Ezzat (amalezzat@yahoo.com), Hope City Foundation (https://b-m.facebook.com/Hope-City-Foundation-HCF)**



<sup>1</sup> www.amshq.org/maria

<sup>2</sup> https://areahearingandspeech.com/about-us



<sup>3</sup> www.espl-egypt.org

## Completion of a Three Year International Project Concerning Communication and Deafblindness Ends with an Expert Conference

## Germany

Ewald Graf

About 100 professionals attended an international conference at Stiftung St. Franziskus Heiligenbronn<sup>1</sup> in the Black Forest on 2nd February 2018. The conference marked the completion of the three-year international project 'EQuaT' that focussed on improving the qualifications of persons communicating with persons with deafblindness. The EQuaT project was funded through the European Union sponsored Erasmus plus program<sup>2</sup>.

Dr. Andrea Wanka<sup>3</sup>, commissioner for deafblindness at Stiftung St. Franziskus Heiligenbronn, was the leader of the networking project EQuaT which started in 2015. While Andrea was on parental leave, Barbara Latzelsberger from the Austrian organization for the deafblind and severely deaf and visually impaired (Österreichisches Hilfswerk für Taubblinde und hochgradig Hör- und Sehbehinderte -OEHTB)<sup>4</sup> took over the network leadership in 2017. In advance of their collaborative EQuaT-project, its members worked together on the PropaeK-



The members of panel discussion, from left: Dr. Andrea Wanka (Project Leader, Stiftung St. Franziskus Heiligenbronn); Professor Dr. Peter Martin (Séguin-Klinik Kehl-Kork); Professor Dr. Karin Terfloth (University of Education, Heidelberg); Ministerialrat Sönke Asmussen (Ministry of Education and Cultural Affairs, Baden-Wuerttemberg); Dr. Maria Brons (Royal Dutch Kentalis) and Barbara Latzelsberger (Austrian Relief Organization for Deafblind and Profoundly Hearing and Visually Impaired Persons (ÖHTB))

project (Professionalization of Pedagogical Concepts), which was also funded by the European Union.

The goal of the participating institutions<sup>5</sup> was to develop a qualification course to develop competent communication partners for persons with congenital deafblindness within the German-speaking area. It is well understood that only highly specialized individualized communication introduced into the daily activities of persons with disabilities will enable these

individuals to improve their chances for participation and enhance their living conditions.

At this final meeting in Heiligenbronn, the partners decided to continue their international collaboration at the University of Groningen in the Netherlands. A pilot training program of 15 working days over a twelve-month period is scheduled to begin in the spring of 2019.

The results of the three-year project were presented to the participants at the international expert

<sup>1</sup> www.stiftung-st-franziskus.de/

<sup>2</sup> Erasmus+ is the EU's programme to support education, training, youth and sport in Europe. Erasmus+ has opportunities for a wide range of organisations, including universities, education and training providers, think-tanks, research organisations, and private businesses. (https://ec.europa.eu/programmes/erasmus-plus/about\_en)

<sup>3</sup> Andrea Wanka is the Chair of the DbI CHARGE Network

<sup>4</sup> www.oehtb.at

<sup>5</sup> (Royal Dutch Kentalis; Rijksuniversiteit Groningen; The Austrian relief organization for Organization for Deafblind and Profoundly Hearing and Visually Impaired Persons (ÖHTB); the Swiss foundation for the Deafblind; German Taubblindenwerk Hannover; Blindeninstitutsstiftung Würzburg; Oberlinhaus Potsdam and Stiftung St. Franziskus Heiligenbronn)



Germany  
continued

The participants of the project at their final meeting in Heiligenbronn

conference in Heiligenbronn. Among the participants were professionals from the institutions involved in the project, as well as professionals from other institutions and public authorities.

The project leaders Andrea Wanka and Barbara Latzelsberger, and representatives from the EQuAT- project working groups outlined the contents of the training program. During workshops, staff from Stiftung St. Franziskus presented insights into the diverse aspects of communication related to persons with deafblindness. This included such aspects as the use of objects of reference, interactions with peer groups, the meaning of bodily-emotional traces, etc.

Through panel discussions, representatives from the Ministry of Education and Cultural Affairs (Baden-Wuerttemberg), the University of Education (Heidelberg), Epilepsy Center (Kehl-Kork)

and Royal Dutch Kentalis (Netherlands) gave positive feedback to the project leaders. They praised their “training model” and encouraged them to spread the course widely.

Two relevant reference books about to be published concerning deafblindness pedagogics were presented by their authors: Inger Rødbroe from Denmark and translator Ulrike Broy-Schwenk introduced ‘Communicative Relations’. Elisa Keesen from Stiftung St. Franziskus Heiligenbronn presented her book, *Angeborene Taubblindheit und die Konstruktion der Welt* (‘Congenital Deafblindness and the Construction of the World’). Both books will be published by Edition Bentheim.

The ideas and topics presented at this conference met with a very positive and inspirational response from the participants. The chair of Blindeninstitutsstiftung Würzburg, Johannes

Spielmann, thanked Roland Flaig, the head of the Services for the Disabled, for his strong commitment to the international transfer of knowledge. He was ceremoniously presented with a medal of honor and an apple tree to be planted in Heiligenbronn. Just like networking, the tree will bear rich fruit!

Looking back on this second successful EU deafblindness project, Roland Flaig suggested that: “In order to successfully complete an ambitious project, first of all one needs a great challenge, followed by visionary ideas and a strategy for their realization. Following that of course is the will for positive results with the obligation to fulfill them.”

**The article was translated by Mrs. Ulrike Broy-Schwenk.**

**For further information, contact: ann-katrin.bihler@stiftung-st-franziskus.de**

## Development of a Professional Training Course for Staff Working in the Deafblind Field in Europe

Persons with deafblindness are highly dependent on others to assist with their communication and mobility needs because of the significant impact that arises from their visual and hearing impairment.

It has now become widely recognized that only competent communication partners, those who are trained and prepared to engage in complex communication processes, can provide the appropriate assistance to persons with deafblindness throughout their lives.

It has become obvious in the field of deafblindness throughout Europe (and within the German-speaking portion in particular) that there is a very real need for a broad and innovative training program for staff in this field to work with these individuals.

Because of the absence of appropriate training courses, staff representing a network of organizations and institutions<sup>1</sup> recently collaborated to develop a Staff Training Program (Mitarbeiter\_innen Schulungs Programm) designed to establish qualifications and competencies for individuals working in the field of deafblindness. The goal of this pedagogical program is to facilitate an improvement to the quality of life of persons with deafblindness.

### Training goal:

The intention of this staff training program is that participants will expand their current level of competency in the field of deafblindness to become expert competent communication partners to assist persons with congenital deafblindness or persons with difficult communication to further develop their communication abilities.

When participants complete their training course as competent communication partners, they should be able to use their newly acquired skills in their daily practice to provide ‘emotionally stable and cognitively fruitful’ communication for communication challenged individuals.

The Staff Training Program was developed based on the four booklets titled ‘Communication and Congenital Deafblindness’ produced by the DbI Communication Network and the new reference book ‘Communication Relations’ written by Inger Rodbroe<sup>2</sup>.

The training course is designed for all staff members who work with

deafblind individuals of all ages. The methods of teaching are based on contemporary methodologies, using the latest findings from adult education and neurophysiology, with the use of video analysis as a central working tool. The course is designed to be completed in 15 working days over a 12-month period. A Pilot course is scheduled for the spring of 2019. The course is a project of EQUAT.

**For further information please contact Ann-Kathrin Bihler: Ann-Katrin.Bihler@stiftung-st-franziskus.de**

*“The methods of teaching are based on contemporary methodologies, using the latest findings from adult education and neurophysiology, with the use of video analysis as a central working tool.”*

<sup>1</sup> Rijksuniversiteit Groningen, Netherlands ([www.rug.nl](http://www.rug.nl)); Royal Stichting Kentalis, Netherlands ([www.kentalis.nl](http://www.kentalis.nl)); DTW Hannover Germany ([www.taubblindenwerk.de](http://www.taubblindenwerk.de)); Blindeninstitutsstiftung Würzburg, Germany; (<https://www.blindeninstitut.de>); Oberlinhaus Potsdam, Germany ([www.oberlinhaus.de/startseite](http://www.oberlinhaus.de/startseite)); Stiftung St. Franziskus Heiligenbronn Germany ([www.stiftung-st-franziskus.de](http://www.stiftung-st-franziskus.de)); ÖHTB Wien Austria ([www.oehb.at](http://www.oehb.at)); Tanne Langnau a.A. Switzerland ([www.tanne.ch](http://www.tanne.ch))

<sup>2</sup> Inger Rodbroe is one of the authors of DbI Communication Network booklets.

## Guatemala

## Continued Growth: An Impact Evaluation of FUNDAL

Álvaro Díaz

For Perkins International's (PI) Latin America and Caribbean Region<sup>1</sup>, 2017 was a special year. For the first time, an evaluation of the impact that our actions have on the children and young people with disabilities we work for, was planned for one of our most beloved programs: FUNDAL<sup>2</sup> (short for Guatemalan Alex Foundation for Children with Deafblindness, after its acronym in Spanish – *Fundación Guatemalteca para niños con sordoceguera Alex*).

During a period of seven months, the PI Monitoring, Evaluation, and Learning team prepared the evaluation tools to be applied. Interviews, observations, reports, and quantitative data were thoroughly organized and systematically analyzed. Finally, findings and conclusions were shared with FUNDAL's board and staff.

This brief article is intended to share with a broader audience the main findings that the impact evaluation shed light on.

### The Project

Perkins International's *Expanding Model Education Services in Latin America* project is a four-year, multi-country, multi-partner initiative being implemented

between 2014 and 2018, developed in alliance with Lavelle Fund for the Blind<sup>3</sup>. FUNDAL is one of the main organizations this project works with.

FUNDAL first opened its doors in 1997 after the son of Hellen de Bonilla, founder of FUNDAL, was turned away from school because he has multiple disabilities. She reached out to Perkins School for the Blind, visited one of our partners in Argentina, and returned to Guatemala inspired to start her own program. Over the next 20 years, FUNDAL sought and received grants and technical assistance from Perkins to strengthen its programs.

With Lavelle Fund for the Blind joining the partnership in 2010, FUNDAL has become the model education program that it is today, with schools in 3 locations – Guatemala City, Huehuetenango, and Quetzaltenango – that serve children with multiple disabilities and their families. It is the only resource on deafblindness and multiple disabilities education officially recognized by the Guatemala Ministry of Education. In recent years, the organization has emerged as a regional leader providing technical advice to peer organizations and governments in countries such as El Salvador, Honduras, and México.



Álvaro Díaz

### Impact Evaluation (IE)

An IE is an assessment of the intended and unintended changes produced by an action, project, program, and/or policy intervention. IEs are mainly conducted for lesson-learning, decision-making, and accountability. FUNDAL's IE was guided in order to know what progress FUNDAL was making towards reaching its output and outcome targets, what impact its activities were producing, and how FUNDAL could be positioned for continued growth in the future.

Mixed methods were used to inform the evaluation. Quantitative data was primarily gathered from project documents with subsequent verification from FUNDAL while qualitative data was gathered through interviews and conversations with key informants. Perkins visited FUNDAL and inclusive school programs to conduct observations and interview key informants. Distance interviews were conducted with FUNDAL's

partners located in México, El Salvador, and Honduras. Data was coded, categorized, and analyzed using a tool that Perkins designed to determine impact at organization, beneficiary, and/or systems levels.

### Key Findings

Perkins found that FUNDAL's activities have had a high level of impact on children with disabilities and their families.

#### FUNDAL has, in the last 3 years:

- Reached 11,117 children and 30,540 parents
- Trained 4,723 teachers
- Advised 134 organizations

FUNDAL has become an influential national and regional leader in Central America, influencing public policies and public institutions. The National Ministry of Health (MOH) and Ministry of Education (MOE) in Guatemala have benefited from the expertise of FUNDAL and consults FUNDAL to improve country-wide public health and education.

FUNDAL regularly trains and participates in interagency exchanges with partners in El Salvador, Honduras and México on good practices for educating children with disabilities, including PI Academy Foundations<sup>4</sup> course in El Salvador, the first certified course in Central America.

FUNDAL, through its Adaptive Design Center,

is sharing their knowledge and skills throughout Guatemala, Argentina, Brazil, Chile, Ecuador, El Salvador, Honduras, Nicaragua, Peru, and the United States. This was an unanticipated and positive outcome of Lavelle Fund's support for FUNDAL.

FUNDAL's national trainings have helped raise awareness and advocacy for inclusion in public schools as well as society, opening doors for children with multiple disabilities and deafblindness to access public schools and services.

### Lessons Learned and Recommendations

The main reason to implement the IE was to identify aspects to improve the performance of organizations. Lessons learned through this process were that FUNDAL:

- Has significant potential to influence education systems in the region and position itself for continued growth in the future.
- Can increase their impact by providing more support and follow-up to their trainings, and other key activities, in order to improve the transfer of knowledge into quality practice in the classroom, ensuring that training outcomes are being achieved.
- Needs careful planning and management to avoid risks of reducing internal resources when increasing the quantity of external trainings and technical assistance.
- Should develop formal

agreements with governments and peer organizations to increase accountability and commitment.

- May enhance the production of adaptive materials and generate income.

This way, we expect FUNDAL to build upon their success and have continued growth in future, with a greater presence in the field of deafblindness, providing knowledge and advice for the development of projects and programs in Guatemala and Central America.

Finally, maybe the most important conclusion of this IE is that building partnerships – yes!, partnerships again! – (in this case, PI, Lavelle Fund for the Blind, and FUNDAL) is the best way to build the future for people with disabilities. Different skills, different competencies, different points of view enrich each other with a same aim.

**For more information contact Álvaro Díaz (alvaro.diaz@perkins.org), Monitoring and Evaluation Officer, Perkins International, Latin America and Caribbean**

Guatemala continued

<sup>1</sup> [www.perkins.org/international/latin-america](http://www.perkins.org/international/latin-america)

<sup>2</sup> [www.fundal.org.gt/](http://www.fundal.org.gt/)

<sup>3</sup> [www.lavellefund.org](http://www.lavellefund.org)

<sup>4</sup> [www.perkins.org/international/academy](http://www.perkins.org/international/academy)



Russia

## Living Paintings / Anima Chroma – Art, Dance and Theater in an Inclusive Performance

The Inclusion Theatre Company of Russia<sup>1</sup> launched the first showing of its latest production 'Living Paintings / Anima Chroma' at the Cultural Forum in St Petersburg in late 2017, followed by its second performance in Moscow in January 2018. Living Paintings/ Anima Chroma is a play about paintings and how people with and without eyesight perceive them.

The Inclusion Theatre Company is a centre for the development of professional inclusive theatre in Russia, bringing together artists and directors of leading drama theatres and its own inclusive troupe. It is a part of Inclusion Arts Centre which also includes Inclusion.School and Inclusion.Laboratory. Inclusion Theatre Company projects use various forms of theatre to enable actors with

different abilities to reach the highest levels of artistry.

Since the first staging of Touch-Ables (2015), Inclusion Theatre has produced six productions<sup>2</sup>. Touch-Ables was created to raise social awareness about Deafblind people in Russia. Three further plays were co-created with three leading drama schools in Russia to explore different forms of theatre with inclusive opportunities: Marriage by Gogol<sup>3</sup>, Seagull by Chekhov<sup>4</sup> and Carmen by Mérimée<sup>5</sup>. The productions were all brilliant examples of how high quality performance erases any limits and stereotypes, uniting actors with various abilities in breath-taking, hilarious, unforgettable plays. The search for best practices and how to apply them in Russian inclusive theatre resulted in creating the sensory

performance 'Four Winds' as a part of accessibility programme with the British director Tim Webb.<sup>6</sup>

The Living Paintings/ Anima Chroma performance involves four deafblind actors who work together with three professional actors. It combines modern dance and animation by Oscar-winning artist Alexander Petrov<sup>7</sup>. The actors express in their dance, the process of the creation of seven paintings from the Hermitage art collection in St Petersburg<sup>8</sup>. Actors in the performance represent the colors that come to life under the artist's brush, turning them into artistic images.

This is the first time in the world that all three components – art, dance and theater – work together, with the deafblind actors indistinguishable from their professional colleagues.

For more information, contact Natalia Sokolova (n.sokolova@so-edininie.org), Head of Public Relations and Fundraising, Deaf-Blind Support Foundation 'Con-nection'



<sup>1</sup> For more information, check out: [www.nationaltheatre.org.uk/sites/default/files/in\\_touch\\_press\\_release.pdf](http://www.nationaltheatre.org.uk/sites/default/files/in_touch_press_release.pdf)

<sup>2</sup> See DbI Review Edition 58, January 2017

<sup>3</sup> [https://en.wikipedia.org/wiki/Marriage\\_\(play\)](https://en.wikipedia.org/wiki/Marriage_(play))

<sup>4</sup> [https://en.wikipedia.org/wiki/The\\_Seagull](https://en.wikipedia.org/wiki/The_Seagull)

<sup>5</sup> [https://en.wikipedia.org/wiki/Carmen\\_\(novella\)](https://en.wikipedia.org/wiki/Carmen_(novella))

<sup>6</sup> <https://www.imdb.com/name/nm1022697>

<sup>7</sup> <https://www.imdb.com/name/nm0678154>

<sup>8</sup> [hermitage-wwww.hermitagemuseum.org](http://hermitage-wwww.hermitagemuseum.org)

## A New Association of Persons with Hearing and Vision Impairment was Recently Established in Moscow

Russia continued



The Association of Persons with Hearing and Vision Impairment was established in Moscow Russia, February 20, 2018. This new association was named "Con-sent".

Two hundred delegates, including deafblind people, members of their families, representatives of Russian public organization that support them, including the Deaf-blind Support Foundation 'Con-nection'<sup>1</sup>, took part in the initial congress.

Previously there was no unified organization for people with hearing and vision impairment in Russia. This unprecedented event will serve to unite not only deafblind people themselves, but also their relatives and friends.

The intent is that the Association members will determine the direction and development of the new organization themselves. They intend to work actively by creating a dialogue with local authorities throughout the Russian regions, asserting

their rights to initiate and implement social projects aimed at improving their quality of life as people with deafblindness. It is equally important that their family members and friends provide support in the process.

The Association was established to coordinate all the projects related to deafblind people throughout all the regions of Russia and provide a means for information exchange among each other. As well it will provide an opportunity for deafblind people themselves to establish control over the implementation of programs serving their needs.

This Association intends to improve interaction with the Russian state to protect the rights of deafblind people. A major part of the work of the association will also be to raise public awareness about the problems these disabled individuals face.

According to Dmitry Polikanov, the President of the

Russian Deafblind Support Foundation 'Con-nection', "The long-term goal of the new Association 'Con-sent' is to create a new model of people with disabilities being those who not only seek support while at the same time being responsible and independent and knowing how to protect their rights'.

The Deafblind Support Foundation 'Con-nection' founded in 2014 has as its mission to serve as a conduit between people with deafblindness and those who can see and hear, by developing and integrating successful solutions and practices to provide these disabled individuals the opportunity for self-realization, personal development and integration into society.

For more information, contact contact Natalia Sokolova (n.sokolova@so-edininie.org), Head of Public Relations and Fundraising, Deaf-Blind Support Foundation 'Con-nection'



<sup>1</sup> Deaf-blind Support Foundation 'Con-nection' ([www.so-edininie.org](http://www.so-edininie.org)) is a small corporate member of DbI



Switzerland  
continued

## Learning New Signs Despite a Hearing and Visual Impairment

### A Pilot course run by SNABLIND<sup>1</sup> using special teaching methods

Language is always changing. New words are constantly being invented and we speak differently today from how we did just a few years ago. Of course, these new concepts also make their way into sign language. Many users of sign language who have a hearing and a visual impairment find it difficult to learn new signs because of their limited vision. A course run by the advice centres for hearing and visually impaired and deafblind people allows them to learn new signs by using teaching methods specially adapted to their needs.

In order to be able to follow other people or interpreters who are signing, you need to know, for example, how Instagram, Bitcoin and vegan are signed. The names of new Swiss Federal Councillors and of well-known people such as Roger Federer also have to be learned.

Sign language experts who are themselves deaf decide which terms or sign names best suit these people. The group of experts meets regularly to define new signs, which are then included in the public sign lexicon<sup>2</sup> and passed on to interpreters.

The difficulty that hearing and visually impaired people have in learning new signs relates to being able to see

them. For example, if the person has a restricted field of vision, the signing area must be reduced in size (visual frame signing). Mouthing and facial expressions also form part of sign language, but people with poor visual acuity cannot see them clearly. They also find it difficult to distinguish between the letters of the finger alphabet. For these reasons, tactile signing helps them to recognise the shape of the hands, the position on the body and the movement.

As a result, in 2017 the SNABLIND advice centres for hearing and visually impaired and deafblind people came

up with the idea of offering its clients a course to ensure that they do not miss out on new signs. The pilot project took place in Zurich and could be run in other regions if there is a demand for it.

The teaching methods were developed by a person with a hearing and visual impairment, a sign language expert/instructor and a rehab specialist. The first requirement for the success of the course was to adapt the speed at which the signs were demonstrated to the participants. If you have a hearing and visual impairment, everything takes longer. We describe this



A support person repeats the sign WLAN to allow the participant to “see” the hands of the signing person in tactile form using her own hands and to identify the shape of the hands and the sequence of movements

**SZBLIND**

Schweizerischer Zentralverein  
für das Blindenwesen

different time requirement as “deafblind time”. In order to prevent the participants from being dazzled and to increase the contrast, everyone, including the course attendees, had to wear plain dark clothing up to the chin. The lighting had to be adjusted so that it was glare-free and the signing took place against a black background. In addition, the instruction was in small groups (a maximum of six participants), which ensured that the course attendees were the correct distance away from the instructor. Each participant was also accompanied by a deaf support person who could sign very well themselves.

Because the finger alphabet can be difficult to understand, the words that were being taught were sent to the smartphones of the participants during the course in an ongoing group chat. This ensured that the word was displayed in the font size and contrast that allowed each individual to read it.

The central part of the course involved demonstrating and reproducing the signs. The instructor first showed the hand shapes, then the position on the body or in space and after this the movement. She showed the sign from the front and from the side, which made the movement easier to see, even if the participant



The sign language instructor is in a well lit situation and sits in front of a black background. She demonstrates a sign and the participants practise among themselves or with their support person

no longer had 3D vision. Each participant’s support person repeated the sign in tactile form, if necessary, to enable the participant to understand the sign properly. To allow a group discussion to take place, the instructor repeated what the participants said, which gave everyone the best possible view of the person who was signing.

On the first day of the course, we learned a lot of things that we could apply during the subsequent days. In the group discussions, people changed seats. The person signing had to come to the front so that everyone could see what was being said. This did not work well and therefore we switched to the “parrotting” system. Discussions within the peer group are important and must not be neglected. The support person had to sit closer to the participant than we had first thought. Only two of the six participants see well enough to be able to sit in the second row. On the next

course day we will try out a new approach. The trainer will sit on an office chair with castors and will move from one participant to the next to demonstrate the new sign herself in accurate tactile form. If the participants’ sight deteriorates further, we will divide them into two groups.

The course has been enjoyable, but it requires full concentration from everyone. However, the break is not just to give people a chance to relax, but also to enable them to talk to their peers.

**Mäde Martha Müller SZB/  
SNAB (mueller@szb.ch)**

*Text also available in German  
and French.*

<sup>1</sup> Swiss National Association of and for the Blind (<http://www.szb.ch/en/>) is a small corporate member of DbI.

<sup>2</sup> <https://signsuisse.sgb-fss.ch/de/>



**Acquired Deafblindness Network**  
<http://adbn.deafblindinternational.org>

**Adapted Physical Activity (APA) Network**  
 Mads Kopperholdt and Anders Rundt  
 Emails: mads.kopperholdt@rn.dk;  
 anmaru@rn.dk)

**CHARGE Network**  
 Andrea Wanka  
 Email: aw@andrea-wanka.de  
<http://chargenetwork.deafblindinternational.org>

**Communication Network**  
 Marleen Janssen  
 Email: h.j.m.janssen@rug.nl  
<http://communication.deafblindinternational.org>

**European Deafblind Network**  
 Ricard Lopez Manzano  
 Email: rlopez@sordoceguera.com  
<http://edbn.deafblindinternational.org>

**Ibero Latin America Network**  
 Vula Ikonomidis  
 Email: vula2004@hotmail.com  
<http://iberolatinamerican.deafblindinternational.org>

**Network of the Americas**  
 Marianne Riggio  
 Email: Marianne.Riggio@Perkins.org  
<http://americas.deafblindinternational.org>

**Outdoor Network**  
 Joe Gibson  
 Email: deafblindoutdoors@gmail.com  
<http://outdoornetwork.deafblindinternational.org>

**Research Network**  
 Prof. Walter Wittich  
 Email: walter.wittich@umontreal.ca  
<http://research.deafblindinternational.org>

**Rubella Network**  
 Nigel Turner  
 Email: nigel.turner@sense.org.uk  
<http://rubella.deafblindinternational.org>

**Social-Haptic Communication Network**  
 Dr. Riitta Lahtinen & Russ Palmer  
 Email: riitta.lahtinen@icloud.com;  
 rpalmer2@tiscali.co.uk  
<http://socialhaptic.deafblindinternational.org>

**Tactile Communication Network**  
 Paul Hart  
 Email: phart@sensescotland.org.uk  
<http://tcn.deafblindinternational.org>

**Usher Network**  
 Emma Boswell  
 Email: Emma.Boswell@sense.org.uk  
 Nadja Högner  
 Email: nadja.hoegner@hu-berlin.de  
<http://usher.deafblindinternational.org>

**Youth Network**  
 Simon Allison  
 Email: simon.allison@sense.org.uk  
<http://dbiyn.deafblindinternational.org>

## Adapted Physical Activity (APA) Network

We understand that the APA network is the youngest of the networks within the DbI. We received the official approval during the European Conference, held in Aalborg, Denmark, September 2017. We are proud to have achieved this and will do our utmost to live up to the standards and guidelines of DbI. The way that we want this network to be dynamic is that each new member will introduce themselves to the group. We call for new theory, different practices and themes of discussions to benefit each participant, and for the benefit of the deafblind society.

To create an open discussion at all times in our network, we have created a closed Facebook group carrying the name of 'DbI & APA'. It is a closed group, because we like the members to introduce themselves in approximately 100 words. Then all members can see who participated and who might be of assistance, be it a similar school or a school in the same geographical area. Everybody within the field of deafblindness and adapted physical activity is welcome to join.

**The aims for our network group are:**

- Participate in an international internet-based forum.
- Exchange knowledge about APA (adapted physical activity).
- Post the latest ideas, news, practical exercises, theory and scientific research.
- Inspire each other to take part in conferences and arrange meetings during the conferences.
- Invite each other to network meetings.



**Within the next year, we hope to take part in the following conferences:**

- [www.pcnnet.org/fagkonference-2018](http://www.pcnnet.org/fagkonference-2018)
- [www.ssc.education.ed.ac.uk/courses/vi&multi/vconf19.html](http://www.ssc.education.ed.ac.uk/courses/vi&multi/vconf19.html)
- We hope to host the first international network meeting at: [www.ableaustralia.org.au/news-events/events/17th-deafblind-international-world-conference-2019](http://www.ableaustralia.org.au/news-events/events/17th-deafblind-international-world-conference-2019)

We hope you will be inspired to join the network and hopefully meet us at these conferences.

**If you want to participate in the DbI & APA Network, please contact us as follows: Mads Kopperholdt (Mads.kopperholdt@rn.dk) or Anders M. Rundh (anmaru@rn.dk)**

## CHARGE Network

We are planning a preconference on August 11th, 2019, in advance of the next world conference in Australia. If you are interested in attending or in giving a presentation, sharing a video, etc. please contact me.

**A CHARGE conference is taking place in France in September 2018.**

**For more information please contact Corinne Boutet (corinne.boutet@cresam.org).**

**Dr. Andrea Wanka (aw@andrea-wanka.de)  
 Chair DbI CHARGE Network**



## Communication Network

Marleen Janssen reports:

**A new and larger DbI Communication Network is almost here. The last year has been one of transition for our network. The following represents the main developments that have taken place in our network since September 2017.**

**Network meeting Communication Network at the Aalborg Conference**

We organized a Network Meeting at the Aalborg conference in September 2017. There we started with a new format. The Nordic Network on Communicative Relations held a magnificent presentation. The core of their content was a video analysis about an interesting case of complex communication. The presenters plan to write a report about their presentation for the next issue of DbI Review. Anni Lise Ellefsen from Norway will be in charge of that.

Following that presentation we had a discussion about how to develop the larger DbI Communication Network in the future. The following ideas were suggested:

- *Share knowledge on Communication* from different countries and different places all over the world. Video analysis of communication with persons who are deafblind is formulated as the main goal.
- Provide a place for *subgroups* within the network, such as: working groups, study groups, research groups, including the former Communication Network and other groups that want to join.
- Open the Communication Network for individual members; not only for professionals but *also for people with deafblindness and parents.*

- Start a *web page* connected to the DbI website (may be also a Facebook page). We hope that many members will join and we'll have an expanded network in the near future.
- Use *English as the main language*, but also open the network for people who use other languages such as the Spanish, Portuguese or Japanese language. It would be great if knowledge could be translated in different languages. But that is more a goal for the longer term.
- Share *ideas in small groups with experienced professionals* from other smaller network groups. So, from different subgroups more contact persons are needed, who can easily contact each other.
- Use *video conferencing all over the world*. We can plan fixed moments to have contact with the network, not only at conferences but also in between. This can be done if we have a *platform* on the website. Individual members and subgroups can then contact each other.

As first *concrete steps* we agreed upon: a) making a mailing list, b) setting up a Webpage connected to the DbI website, c) plan concrete meetings with concrete topics. If subgroups want to make a report for DbI Review they can send their report first to the chair of the network. These reports will then be used for the Network report that is sent to the information officer of DbI.

### Becoming a member of the Communication Network

At this moment, we are still in the phase of making a website and trying to reach as many members as possible. We will start with the list of the people who were in Aalborg, but the Communication Network is open for everybody. You can contact the coordination team if you want to become a member. The coordination team at this moment exists of: Herma Arends, Saskia Damen and Marleen Janssen. Soon we will have a separate e-mail address, but for now you can mail to: [h.j.m.janssen@rug.nl](mailto:h.j.m.janssen@rug.nl).

### CONCRETE ACTIVITIES

#### Newsflash

Herma Arends will start a Newsflash for our Communication Network at our own website linked to the DbI website, so if you have news to announce you can use this website.

#### DbI Review Book on Communication: overview of 40 years

In Aalborg we decided to fulfill a wish of the DbI Board to make a book of all interesting articles about Communication published in the DbI Review for the last forty years. I am in the

starting phase to get access to all these articles. I think it would be great if the book will become digitally accessible. If you have good suggestions for interesting articles, please let us know.

### CONCRETE MEETINGS

#### Preconference Australia

On Saturday August 11, 2019 we will organize a preconference at the conference in Australia with the theme: Video analysis and Video feedback in Communication. If you plan to join this preconference you can apply. If you have ideas for a contribution, you can let me know. We have already some contributions from Japan and the Netherlands; more ideas are very welcome.

#### Network meeting Australia

On Wednesday August 14 in the afternoon we are planning a meeting of the Communication Network. We do not know the details yet, but the main goal is to have a presentation on video analysis of communication and after that to discuss good ideas for: a) expanding the members of the Network, b) planning concrete meetings with concrete themes, and c) how to use social media to better share knowledge around the globe.



### REPORTS FROM THE SMALLER NETWORK GROUPS

#### Groningen Group – Study group on Congenital Deafblindness and Diversity in Communication by Paul Hart

At the 2017 DbI conference in Denmark, the new DbI Communication Network was launched. Initially it will be coordinated by Marleen Janssen from the University of Groningen. There are many exciting developments in communication taking place all across the world, in relation to both congenital and acquired deafblindness. The DbI Communication Network aims to provide a meeting place for all those developments so that various groups can all learn from one another. It is hoped that the umbrella DbI Communication Network will comprise of many smaller groups who will consider specific aspects of communication – these groups may work autonomously or from time to time they may work together on ideas. And that is where the real power of any DbI Network lies – how these groups all share ideas with each other so that we can really push forward our thinking about authentic communication. Some of these groups are likely to come together at DbI World Conferences or regional conferences as part of the larger DbI Communication Network to offer pre-conferences and network days. Indeed, like any DbI networks, the Communication Network may host an entire conference on communication. All of this is for network members to decide.

Most of you will know that this new larger Communication Network has grown out of the original DbI Communication Network, which originally started as a European

Working Group on Communication. This group will continue and become one of the groups that are members of the larger network. It will be known as the Study Group on Congenital Deafblindness and Diversity in Communication or the Groningen Group, because that is where most meetings of the group take place and where much of its current work is focused. The members of this group (Marleen Janssen, Marlene Daelman, Jacques Souriau, Anne Nafstad, Paul Hart and Flemming Ask-Larsen) are almost all connected to the Masters course in Communication and Congenital Deafblindness delivered by the University of Groningen in The Netherlands, under the direction of Professor Janssen.

There are already various elements that are connected to this overall program of work:

- Delivery of the Master's course each year, with many exciting theses written by students (mostly relating to congenital deafblindness but some theses have directly involved people with acquired deafblindness and has everyone to learn new insights into the diversity of human communication)
- An active Alumni network of previous graduates of the course who organise their own events and collaborate regularly on their own projects across borders
- Publication of the Journal of Deafblind Studies on Communication (available at <https://jdbsc.rug.nl/>)

In the future, the group plans to develop additional modules and run short-courses at a post-masters level.

**We know there is equally exciting work happening all across the world so we would encourage everyone who is already developing new ideas and approaches to communication to**

**get in touch with Marleen Janssen ([h.j.m.janssen@rug.nl](mailto:h.j.m.janssen@rug.nl)) or look up information on the networks section of the DbI website. The future is exciting and together with other DbI networks, we can look forward to a continued learning and sharing of ideas.**

#### Alumni network Master deafblindness by Saskia Damen

On Wednesday the 14th of March the alumni network organized a seminar on communication development and language acquisition at the University of Groningen in the Netherlands. The organizing committee consisted of Jacky Smith, Annika Johannessen, Jonathan Reid and Saskia Damen. The seminar was organized for alumni and current students of the Masters and was also open for staff and students of the University and professionals working in the field of deafblindness.

The seminar started with a welcome and introduction by Jonathan Reid. Second, was a plenary lecture by Dr. Jude Nicholas, Clinical neuropsychologist at Statped & Haukeland University Hospital Bergen, Norway and researcher at Central Michigan University, titled “**The sense of touch: it's importance to cognition and social communication**”. In his lecture Jude Nicholas explained that the human sense of touch is an active, informative, and useful perceptual system. According to Jude, touch is our most social sense, and it provides us with our most fundamental means of contact with the external world. He states that interpersonal touch plays an important role in governing our emotional wellbeing and that the sense of touch provides us with an often-overlooked channel of communication.

After the lecture, a case study was presented by Annika Johannessen, consultant deafblindness from Statped Norway. Annika presented a video in which an individual with deafblindness learned the linguistic concept of a tree as a result of bodily-tactile rehearsal strategies, linguistic input and reminiscing. In the afternoon, Saskia Damen, researcher at the University of Groningen, held a presentation on competencies of communication partners. In the presentation she showed research findings with regard to effective ways to support communication partners and discussed implications for research and practice. After this presentation, participants worked in small groups to analyze videos, using concepts that were presented in the lectures.

On Wednesday 15th of March an alumni network meeting was held. Here it was discussed which activities are relevant for the network and how to keep in touch. This resulted in the start of a facebook page Deafblind Masters Alumni Group by Jonathan Reid. Also, it was decided to already plan the next alumni seminar on September 26 and 27, 2018. The seminar will be organized in connection with the graduation day of the students of the Masters of Communication and Deafblindness in Groningen. This will enable the attendees of the seminar to hear the presentations of the masters projects. The topics for next seminar are ‘partner competencies’ and ‘the role of art’. The seminar will be open for alumni and other professionals interested.

**For more information please contact the alumni network: [alumninetworkcdb@gmail.com](mailto:alumninetworkcdb@gmail.com)**

**“I hope you have some patience with our network plans, but soon we will be open for everybody who is interested.”**

**I hope you have some patience with our network plans, but soon we will be open for everybody who is interested. For more information contact Marleen Janssen, on behalf of the DbI Communication Network Team: [h.j.m.janssen@rug.nl](mailto:h.j.m.janssen@rug.nl).**



### Master of Communication and Deafblindness by Marleen Janssen

In 2017 another 7 students graduated for this master. Here is an overview of the graduated masters and their topics:

- Julia Usselman (Germany): It's about having a voice! How can caregivers of persons with deafblindness master the concept of agency?
- Caroline Lindström (Sweden): Contributing to a bodily/tactile language by transforming cultural customs.
- Lucia Oostra Urrea (Colombia): Positive and negative factors on peer interaction for children with deafblindness.
- Leendert van Dam (the Netherlands): A place to be – Research to the quality of life of persons with deafblindness living in institutes for mentally retarded persons.

- Marianne Rorije (the Netherlands): My mind knows: we all have different minds.
- Manon Steltenpool (the Netherlands): Declare you and me – A study about the influence of different professional roles on declarative communication.
- Wolfgang Hug (Germany): "I have a dream" – Integrating wishes and passions of adults with deafblindness into the consultation process.

During this academic year (2017–2018) most students are from Norway, with several also from DR Congo and the Netherlands. Students and lecturers are working at this moment very hard in finishing and supervising the master theses. Again we have very interesting topics to look forward to, for example: The use of

sign language in communication with children who are congenital deafblind; The cultural position of people with deafblindness in East and Central Africa; Creating the context for people with congenital deafblindness to share memories of loved ones who have died; and Assigning meaning to tactile observable images and symbols. The graduation day will be on September 26, 2018. It is still possible for new students to apply for this master track in Pedagogical Sciences Communication and Deafblindness for the academic year 2018–2019. And of course new students can apply for the year 2019–2020. They can contact the academic advisor at the University of Groningen, Alette Arendshorst: A.M.Arendshorst@rug.nl.

## DbI Research Network

### Walter Wittich reports:

The DbI Research Network is moving into its fourth year of existence, and we continue to grow and expand. As of May 2018, we now have 110 members on our e-mail contact list.

Saskia Damen and Flemming Ask Larsen continues to maintain the Deafblind International Research Network Facebook Group ([www.facebook.com/groups/158743377516989/](http://www.facebook.com/groups/158743377516989/)), which currently has 202 members and growing. Come look us up and join in the conversation! Christine Lehane continues to maintain our Deafblind International Research Network LinkedIn group ([www.linkedin.com/groups/8339092/](http://www.linkedin.com/groups/8339092/)), which currently has 57 members.

The Action Research Working Group, led by Susan Bruce continues to promote collaborative opportunities, and you can learn more about her efforts on our Research Network web page. Additional initiatives are always welcome, so please get in touch with any of the members of the DbI Research Network, in case you have an idea you would like to share.

The network members have begun to organize the research activities that are planned to be part of the next DbI International conference in Gold Coast, Australia, in August of 2019, which will likely include: a Pre-Conference Research Workshop, a Research Network Session and a Research Forum as part of the conference itself. This will be an

opportunity to re-visit the research priorities that were discussed by attendees at the recent 9th European Deafblindness conference in Aalborg, Denmark, where Saskia Damen and Flemming Ask Larsen hosted the Research Network session.

Until then, if you have any ideas for us, or other requests for research-specific information, we look forward to hearing from you, and please feel free to check out the networking opportunities on our web page and contact us with your interests and thoughts.



**Walter Wittich**  
([walter.wittich@umontreal.com](mailto:walter.wittich@umontreal.com))  
on behalf of the  
**DbI Research Network Team.**

## DbI Outdoor Network

### Joe Gibson reports:

This has been a quiet period for the Outdoor Network. Here in northern Europe we have come through a long winter and are beginning our summer activities. The planning for this year's Outdoor Week is well under way. This year's the event will be held in Sømådalen<sup>1</sup> in Norway with the details as follows.

### DbI Outdoor Network Outdoor Week, 2018

#### DATES

Week 38 17th–21st September 2018

#### LOCATION

Johnsgård Tourist Centre, Sømådalen, Norway  
<http://www.johnsgard.no>

#### PRICE

4000 NOK per person, includes four nights accommodation, food and activities

#### ACTIVITIES

Activities will include, fishing, canoeing, outdoor cooking, making traditional food (butter and flat bread), frisbee golf and hill walking

#### CONTACT

Reidar Martin Steigen [reidarms@online.no](mailto:reidarms@online.no)

This past May the Nordic Welfare Centre<sup>2</sup> ran a course on Meaningful Activities focused on outdoor activities. As a result of this event, the Outdoor Network now has many new members. There are now currently over 140 people on the mailing list and over 150 on the Facebook page. The address for the Facebook page is: <https://www.facebook.com/groups/771554296237459/> and can be searched for as: Outdoor Network, Deafblind International.



If you wish to find out more about the Outdoor Network or join the mailing list, please contact Joe Gibson at [deafblindoutdoors@gmail.com](mailto:deafblindoutdoors@gmail.com)



<sup>1</sup> <https://no.wikipedia.org/wiki/Sømådalen>

<sup>2</sup> The Nordic Welfare Centre (<https://nordicwelfare.org/en/about-us/>) is a small corporate member of DbI.



## Usher Network

Emma Boswell reports:

The Usher Network members are making plans for another exciting Usher Network Pre-conference in Australia next Summer 2019. More details to follow in the next edition of DbI Review. If anyone would like to be on the mailing list, please do contact Emma to be added to the list.

In the meantime we are thrilled to welcome Alana Roy as a new member of the Usher Network. Alana Roy is a registered Psychologist, Mental Health Social Worker, Counsellor, Advocate, Teacher and PhD candidate specialising in Deafblind research methodology. She is completing a Diploma in Auslan. Alana is passionate about working with trauma, suicide prevention, disabilities, mental health and wellbeing for children, youth, families and adults. Alana can be reached at: [alana@thesignsoflife.com.au](mailto:alana@thesignsoflife.com.au)

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**As part of my report, I am adding this personal story which happened on the train**

Have attitudes towards disabled people within society (UK) REALLY changed in the last few of decades?

I was returning from a meeting in Birmingham recently when I had an 'exchange' with a lady on the train. The lady was travelling with her three children (and lots of luggage) and she reacted angrily to my request to move seats. We were all boarding at Birmingham, the lady was in front of me as we piled



onto the train. Unfortunately, as I got through the doors and found my way to my reserved seat at the front of the coach, the lady and her three children were already sitting there. I was standing to the side of the table, in the aisle, with my guide dog, Bella by my side and my interpreter behind me. She reacted rudely when asked if we could sit down.

There were two people in front of me but they decided to walk away quietly as the woman angrily picked up her bags and pushchair and her bewildered children.

As you know there is limited space on trains, Bella and I had to lean to the side to let her past, she stormed around swearing saying we should have told her before she sat down (we were in the corridor at the time) and we waited for the mother and children to move.

On her way past she burst out; "She should have been put down at birth." My interpreter who was behind me at the time, trying to move into the right seat looked shocked. I was completely unaware of her comments as I too was trying to sit down and manoeuvre Bella under the table, but I knew to be cautious because of the lady's body language. She and her kids left the carriage with an air of anger. We sat down and the

interpreter told me exactly what she had said. The two women who were behind us in the queue to get on the train sat down next to us, they were shocked too as they had heard the lady's comments, and to add insult to injury as one of their relatives are deaf!

I felt strangely calm and not bothered by her comment, but I had to tell myself that I am proud of my achievements and love the life that I am leading so I did not feel any bitterness towards her. Perhaps another person with Usher in my shoes may have reacted differently – perhaps they would have got upset or other emotions may have risen? Is this hate crime? Should I have reported it?

I decided to leave it and get on with my journey, but it got me thinking. One thing that hit me is has society really changed its attitude towards disabled people, especially in the last few years. Sometimes it feels like things are going backwards in terms of attitude, especially with the benefit scrounger rhetoric<sup>1</sup>, benefit sanctions, ATW<sup>2</sup> caps and problems with PIP payments and appeals<sup>3</sup>. There is also anecdotal evidence that there is a marked rise in disability hate crime and it can't be a coincidence that these things are happening in parallel.

We must remember that we as disabled people have rights and we must support disabled people and deafblind people especially when they may face disability hate crime.

**Emma Boswell, Usher Network Leader**  
([emma.boswell@sense.org.uk](mailto:emma.boswell@sense.org.uk))

<sup>1</sup> <https://www.disabilitynewsservice.com>

<sup>2</sup> <https://www.deafatw.com/updates.html>

<sup>3</sup> <https://www.scope.org.uk/Support/Tips/Disabled-people/PIP-appeals>

## Youth Network Report

Simon Allison reports:

The youth Network (DbIYN) is busy preparing for two events this summer, 2018. In June there will be a group activity held in Zurich, Switzerland. The event is being hosted by TANNE, the Swiss Centre of Competence for the Deafblind. Activities already planned include a cruise on Lake Zurich, Lindt chocolate factory tour, Zurich spa and thermal baths, mountain train trip, Swiss National museum visit and old city tour. The event will also include a mini conference with youth network

members discussing their services in their individual countries and future planning for youth network events.

Moving on to July there will be the second part of the Australia / UK Youth Network exchange visit. The visit will take place in Cornwall England and the initial group of young people who went over to Australia in 2015 will be hosting their visitors. The group from Australia will also have the opportunity to take part in a specially arranged visit of the Houses of Parliament in London (UK).



Full details of both these events will be published in the next edition of DbI review.

**For more information, contact**  
[Simon.allison@sense.org.uk](mailto:Simon.allison@sense.org.uk)



***“The visit will take place in Cornwall England and the initial group of young people who went over to Australia in 2015 will be hosting their visitors.”***



# A New Era for Perkins International Latin America and the Caribbean

Gloria Rodríguez-Gil, Karina Medina, Marta Elena Ramírez and Ana Lucia Rago

In 2017 Perkins International Latin America and the Caribbean (PI LA&C)<sup>1</sup> restructured their regional activity, launched Perkins International Academy (PIA)<sup>2</sup> and are organizing strategic meetings and conferences with the purpose of joining efforts with governments and civil society to train 130,000 teachers in 18 countries in LA&C and to 500,000 children and youth with MDVI by 2030.

Perkins International (PI)<sup>3</sup> is re-aligning their work to meet the UN Sustainable Developmental Goals (SDG's) or Global Goals for 2030<sup>4</sup>. This re-alignment will focus particularly on Goal No. 4 that seeks to achieve "inclusive and quality education for all"; and more specifically towards target 4C which states: "to substantially increase the supply of qualified teachers". The intent of the International Academy (PIA) is to satisfy this purpose.

**We are taking actions in five directions to reach our goal:**

## 1. Restructuring Latin America and the Caribbean (LA&C)

We have divided the Latin America and the Caribbean (LA&C) into three sub-regions with the intent of locating personnel with deep understanding of the needs and strengths of each region closer to the national key stakeholders and national and international cooperation organizations.

### The 3 regions are:

- México, Central America and the Caribbean with the PI Representative Marta Elena Ramírez located in Querétaro, México;
- Brazil with the PI Representative Ana Lucia Rago located in Sao Paulo, Brazil;
- South Cone and Andean Region with the PI Representative Karina Medina located in Córdoba, Argentina.



## 2. Perkins International Academy

In 2017 PI launched a new global teacher training initiative to address the shortage of trained teachers who could provide appropriate educational services to children and youth with vision loss, additional disabilities including those with deafblindness.

The courses called 'Education of Learners with Multiple Disabilities and Sensory Loss' are divided into three levels – Foundations, Advanced, and Program Development. For Perkins with 97 years of international teacher training expertise, this was the first-ever international competency course for teachers working with this specific population.

LA&C is about to begin our sixth training course involving professionals

from seven countries. The following testimonies are from professionals who have taken the course from each of the three sub-regions.

- *PIA was my first opportunity to receive systematic training in the education of students with multiple disabilities. The opportunity for distance learning, the dynamic presentation of the different topics, the publications and videos offered were important sources of information that I will treasure and to which I will continue to turn to for deeper analysis. (Sonia Beron, Teacher, Río Cuarto, Argentina)*
- *It was in 2017 when I was presented with the opportunity to receive certification on multiple-*



Gloria Rodríguez-Gil



Karina Medina



Marta Elena Ramírez



Ana Lucia Rago

*disabilities from Perkins, which I did not hesitate to accept. I discovered with the training that my student Zoe could make achievements despite the challenges that she faced. The most important thing for me was to understand first that Zoe was a whole person and that I needed respond to her needs for her to accomplish something meaningful. (Kimberly, teacher, Guatemala).*

- *I had the pleasure of being invited to be one of the tutors of Perkins International Academy in Brazil. The launching of PI Academy is a dream come true for the professionals who have already been working in the field of Deafblindness and Multiple Disabilities. This course will enable us (the tutors) to reach other professionals who don't have this specific training, but still work with this population. (Laura Lebre Monteiro Ancillotto, PIA tutor, Brazil)*

## 3. Establishing Model Programs

With PI Academy, PI intends to create model programs together with various government agencies and NGO's in each of the regions. There will be educational centers that will provide model educational services; where practitioners will receive training, make observations and practice, and share best practices. These model centers will

have strong outreach services to serve the larger community, actively participate with families and create evaluation tools that will further help guide educational planning.

## 4. Monitoring, Evaluation and Learning (MEL)

PI is increasing its monitoring, evaluation and learning (MEL) capacity by:

- establishing a learning portfolio, developing a comprehensive pre – and post-testing assessment process, as well as a follow-up evaluation for Perkins International Academy;
- performing program, country and regional wide evaluations to help understand the current situation. This is intended to guide PI's work and that of others as we move forward having more and better trained teachers and consequently an improved the educational service for population we serve.

## 5. Strategic Meetings and Conferences

PI intends to bring together all the key stakeholders, including government officials from various ministries and secretariats, representatives from universities and local school districts, experts from other disability fields, parent groups and other interested parties who advocate for the rights for the education of children and youth with vision loss and additional

disabilities including those with deafblindness.

Our overall purpose is to ensure the continuation and growth of educational opportunities for this population through to and beyond 2030.

### Some examples of these activities include:

- Creating a National Forum on Individuals with Multiple Disabilities and Deafblindness in Mexico by coordinating groups from the Mexican Civil Society (COAMEX, ASOMAS, CEMDYS, Comunidad Crecer) and Universidad Nacional Autónoma de México (UNAM). Together this resulted in 'inclusion' being recognized for the first time by this group in the CRPD Mexico Shadow Report for 2018<sup>5</sup>.
- Participating in The Network of the Americas International Conference (April 2018) organized by PI and DbI (Deafblind International) which brought experts from all the Americas together sharing their expertise and networking in the field of deafblindness.

Organizing the International Conference 'Utopia and Challenges of Inclusion' in Córdoba Argentina together with the local government (Dirección de Educación Especial y Hospitalaria de Córdoba) and the public university (Universidad Provincial de Córdoba) Department of Education and Health.

<sup>1</sup> [www.perkins.org/international/latin-america](http://www.perkins.org/international/latin-america)

<sup>2</sup> [www.perkins.org/international/academy](http://www.perkins.org/international/academy)

<sup>3</sup> Perkins International ([www.perkins.org](http://www.perkins.org)) is a large corporate member of DbI

<sup>4</sup> <https://sustainabledevelopment.un.org/?menu=1300>

<sup>5</sup> <https://www.globaldisabilityrightsnow.org/tools/crpd-shadow-report-guidance-Mexican-Government's-Implementation-of-CRPD>

**Conclusion**

The goal of PI-LA&C is to train 130,000 teachers in 18 countries of Latin America and the Caribbean to reach 500,000 children and youth with Multiple Disabilities and Visual Impairment (MDVI) by 2030. We can only accomplish this through the commitment of representative governments, along with the support from civil society and various national and international organizations. We want that this population of children and young adults receive quality educational services to provide them the opportunity to have active and engaging lives with their families and communities.

The changes we have already started will evolve as we face the realities of the Region. We need to recognize that the LA&C Region presents widely diverse characteristics, including geography, social structures, and cultural and political institutions, which together will significantly influence the strategies that will be implemented to achieve the proposed goals.

Furthermore, we need to procure the resources with key stakeholders to enable PI to accomplish these objectives despite facing the great challenges. There is no doubt that the world is moving forward with respect to the rights of people with disabilities, if the following are any indication: Convention of the Rights of the Child (1989), The UNESCO Salamanca Statement (1994), the Convention on the Rights of Person with Disabilities (2006) and the Sustainable Development Goals (2016).

We need to continue taking action by moving the needle further to reach the ultimate goal which is: **an appropriate education for all.**

# Impact of Perkins' Website as a Resource for Families and Professionals in Latin America and the Caribbean

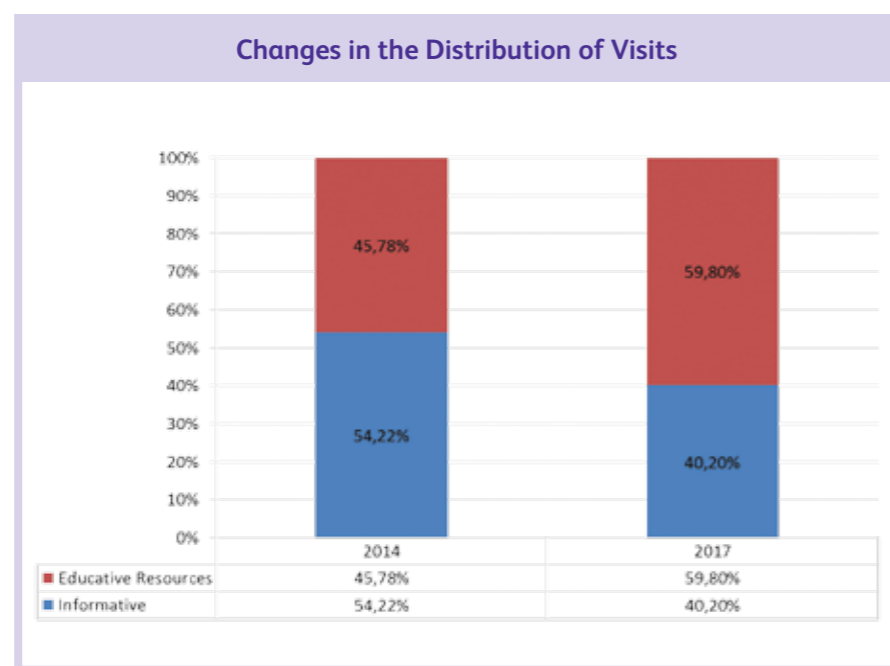
Paula Rubiolo (paula.rubiolo@perkins.org)

Álvaro Diaz (alvaro.diaz@perkins.org)

*Regional Center – Latin America and the Caribbean Latin America and the Caribbean*

Our website [www.perkinsla.org](http://www.perkinsla.org) was initially launched in 2010. The main goal was to provide a space to share and exchange resources and materials in Spanish and Portuguese about the education of children with multiple disabilities and deafblindness.

We created a special team including a content manager and a programming technician to work with the rest of our personnel to provide program content from throughout the region. As shown in the table below (**Changes in the Distribution of Visits**), most visitors to our site in 2017 (59.8%) currently are searching for educational resources.



Source: Google Analytics, March 2018

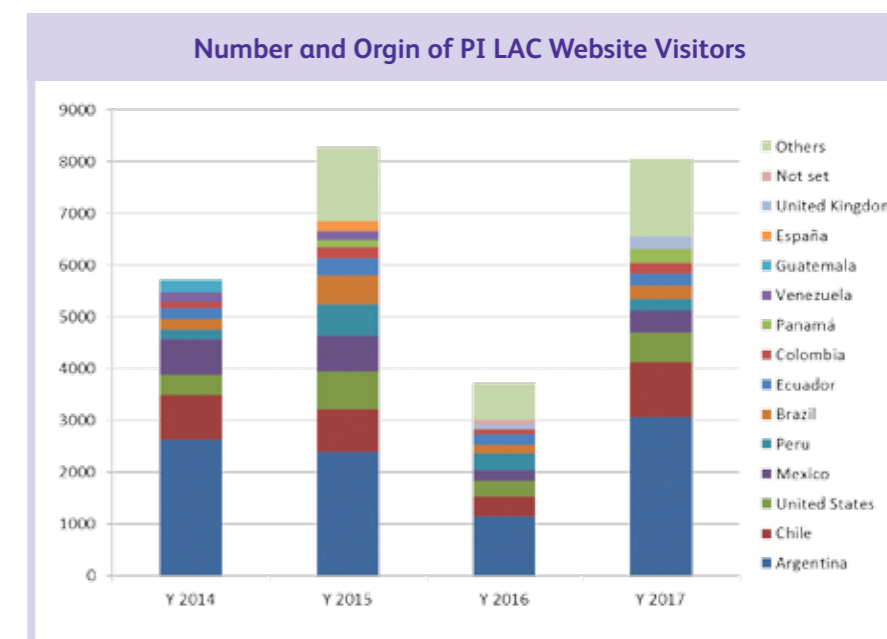
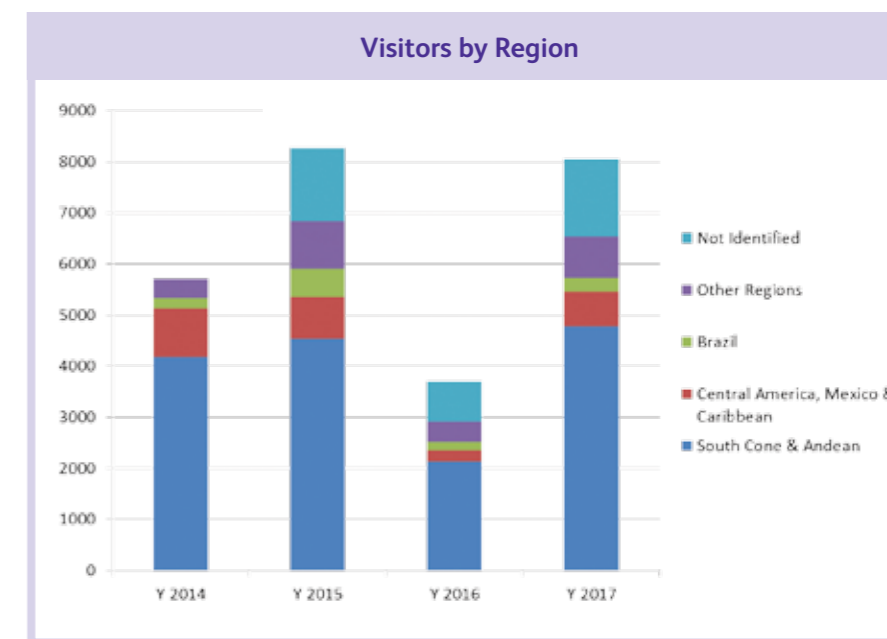
**Significant Changes over time to the Website**

Through the years our website has expanded to meet the changing needs of our users: families, professionals and people searching for training in the subject.

- In 2010, we started the website with an initial design that included the most relevant information available at that time.
- In 2013, the website further developed to provide a reader-friendly format, modified to make the information more accessible for readers. The website then including scanned resources from our regional office library.
- In 2014 we developed an online virtual classroom for delivering specialized courses.
- In 2015 a major redesign of the site occurred to make it look similar to the official website of Perkins School for the Blind. In addition, we made the website mobile friendly, linking it to the Perkins website and Twitter account and other sites such as WonderBaby.org.
- A major step occurred in 2016 when we launched Perkins International Academy (PIA) online and began to deliver PIA Certified Courses throughout the region.

**Our Visitors**

While our online visitors come mainly from Spanish and Portuguese speaking countries in Latin America and the Caribbean, the site also has visitors from other countries around the world. The following table (**Visitors by Region**) shows the distribution of visitors according to regions. Latin America and the Caribbean for our purposes is divided into 3 sub-regions: México, Central America and the Caribbean; Brazil and the South Cone/Andean Region.



Source: Google Analytics, March 2018

Approximately 60% of the visitors come from the Spanish speaking countries of South America (South Cone and Andean sub region). The others two sub regions, Brazil, and México and Central America, have a much lower participation rate at this time, but this is expected to increase due to the new presence of Perkins Representatives in these sub-regions.

The table (**Number and Origin of PI LAC Website Visitors**)

presents a frequency distribution of the extent of visitation to the website from various counties in Latin America and around the world.

**Training Opportunities**

**Webcasts**

Because of the increased demand for trainings in the region, we have produced a series of free and easily accessible webcasts for the website featuring different topics of interest.



These webcasts are presented in Portuguese or Spanish with subtitles in the other respective language.

Current Topics included in the webcasts are:

- Siblings (2014)
- Orientation and Mobility; Social and Educational Inclusion (2015)
- Beyond a dream (non-profit associations); Low vision and multiple disabilities (2016)
- Early Literacy: A Right for All; Adapted designs (2017)

#### One-topic courses

Some topics related to the education of people with deafblindness and multiple disabilities were developed in a more detailed way.

Eleven courses were developed (between 2014 and 2016) and organized into 3 major categories: Learning Challenges, Deafblindness and Multiple-Disabilities and Technology and Adaptive Design.

They are listed as follows:

#### Learning Challenges:

- Teaching strategies for students with disabilities
- Early literacy... an opportunity to access culture
- Approaching the reality of students with multiple disabilities in the south of Argentina

#### Deafblindness and Multiple Disabilities:

- What do we know about people with multiple disabilities?
- Visual strategies for children with low vision and multiple disabilities
- Transition to adult life... the challenge of starting earlier!
- Visual strategies for children with low vision and multiple disabilities – 2nd cohort
- Deafblindness and multiple disabilities

#### Technology and Adaptive Design:

- Technology vs. Disability
- Introduction to adaptive design (workshop)
- Assistive technology in minutes

Individuals from sixteen of the nineteen countries of Latin America have participated in these courses. Those countries not having participants were Bolivia, Cuba and Nicaragua.

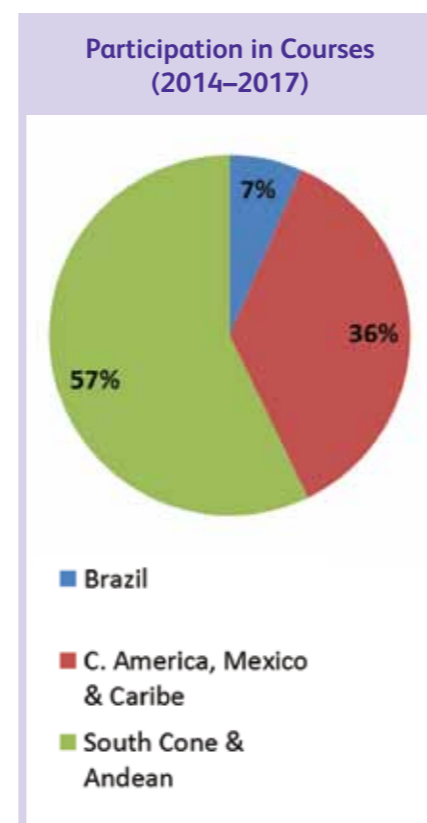
The category of **Deafblindness and Multiple Disabilities** witnessed the most individuals participating in related courses. Courses in the category of **Technology and Adaptive Design Deafblindness and Multiple Disabilities** had the second most participants.

According to the following graphic (**Participation in Courses 2014–2017**), the highest participation rate according to PI division was South Cone and Andean Region (57%), followed by Central America, Mexico and Caribbean Region at 37%, with Brazil participants representing 7 percent.

#### PI Academy Courses

The certified courses of PERKINS INTERNATIONAL ACADEMY began to be delivered through the website platform, as of 2017.

Two courses were delivered (one in Mexico and the other in Ecuador) which together included more than 50 participants from different countries throughout the region.



Source: Google Analytics, March 2018

#### Going Forward

In 2018, we are planning new changes to the website, including expanding the capacity and making the site more practical and useful for users.

Our goal remains unchanged. We want the web page to respond to the needs of families, professionals and other people connected to the field of deafblindness and multiple disabilities making it a most useful tool for this population.

.....  
 We are waiting for you at: [www.perkinsla.org](http://www.perkinsla.org)



Paula Rubiolo



Álvaro Diaz

## An Emergency Intervenor Services Program (EISP); an Essential Step Towards Meeting the Needs of the Deafblind Community

### Janine Tucker

In 2014, CNIB<sup>1</sup> Deafblind Community Services (CNIB DBCS)<sup>2</sup> launched a one-of-a-kind emergency intervenor service in Ontario, Canada. In 2018, the program continues to enhance its ability to dispatch intervenors during a crisis and hopes to collaborate with other intervenor service providers to better meet the needs of the Deafblind community across the province. As we know, when someone who is Deafblind is in a state of emergency, the need for an intervenor is critical.

Prior to 2014 and the implementation of a formal emergency service, CNIB DBCS intervenors responded to emergencies. However, there was often a considerable time delay in getting an intervenor to the scene. Typically, this was precipitated with a great deal of confusion from the perspective of the first responders regarding the accessibility needs of the person, the service provider and contact information. Often, the person who was Deafblind would try to reach one of their regular intervenors or a manager. This attempt wasn't efficient, especially after-hours and over-the-weekend, and it resulted in significant time delays. In some cases, intervenor service wasn't provided.

In Ontario, we are fortunate to have the support of the Ministry



Janine Tucker

of Community and Social Services (MCSS)<sup>3</sup>, which recognizes and respects the rights of people who are Deaf and Deafblind. MCSS funds interpreting services (regular service and after-hour emergency requests) and intervenor services (regular intervenor service for people who live with congenital and acquired Deafblindness, and the CNIB DBCS Emergency Intervenor Services Program). In 2017, 23 transfer payment agencies in Ontario received funding for intervenor services. This is an outstanding level of support compared to other parts of Canada and around the world.

Years ago, MCSS established an Intervenor Services Advisory Group (ISAG). Participants include various members of the Deafblind community and representatives from the larger intervenor service

providers e.g. CNIB DBCS, Deafblind Ontario Services<sup>4</sup> and the Canadian Deafblind Association – Ontario Chapter<sup>5</sup>. At an ISAG meeting, the need for a formal 24/7 emergency service was identified.

So, in 2013, MCSS approached CNIB DBCS and requested a proposal outlining how an emergency intervenor program could work. CNIB DBCS started with an emergency service that would focus on supporting the acquired Deafblind community members who receive services from CNIB DBCS. This reflected MCSS' view that CNIB DBCS's clientele were impacted the most by the lack of a formal emergency service. Some of the other agencies had 24/7 intervenor support for their clients (e.g. people living in a group home setting) or other systems in place to support their clients.

The first step, which MCSS requested, was to conduct a Needs Assessment to identify the number of people we assist with their geographic locations mapped out, plus the number of intervenors we employed and their geographic locations. This would allow us to analyse whether we had an appropriate number of staff in each region to provide support if an emergency occurred. This helped us identify areas where we could prioritize our recruitment efforts.

<sup>1</sup> Canadian National Institute for the Blind ([www.cnib.ca/](http://www.cnib.ca/)) is a small corporate member of DbI

<sup>2</sup> <https://deafblindservices.ca>

<sup>3</sup> <https://www.mcsc.gov.on.ca>

<sup>4</sup> Deafblind Ontario Services ([www.deafblindontario.com/](http://www.deafblindontario.com/)) is a large corporate member of DbI

<sup>5</sup> Canadian Deafblind Association-Ontario Chapter ([www.cdbaontario.com](http://www.cdbaontario.com)) is a large corporate member of DbI

The second step was to reflect on past experiences. What have the successes and challenges been in responding to emergency intervenor requests in the past? What obstacles does a person who is Deafblind face during an emergency?

The following outlines some of the common issues we considered and the potential solutions to address them:

- lack of awareness within the community at large regarding the needs of people who are Deafblind and the role of an intervenor
  - Solution: the creation of scenario-based videos for awareness training with first responders, in addition to EISP brochures and posters.
- confusion as to a person's disability; it may be easy to ascertain that someone is Deaf if sign language is being used, or someone is blind if a white cane is being used, but it's often difficult to determine whether someone is both deaf and blind. This is often realized after much confusion and/or frustration from both parties. This confusion is compounded if a member of the Deafblind community uses speech. People often assume, innocently so, if someone speaks, they must be able to hear. Someone may question why this person would need an intervenor and wonder why they can't communicate effectively if they use speech.
  - Solution 1: Provide the person who is Deafblind with assorted items that can quickly identify them as being Deafblind and indicate how to communicate with them.
  - Solution 2: Ask MCSS to provide financial assistance to people who can not afford MedicAlert<sup>6</sup> (both the pendant/bracelet and the membership

fee). Since first responders are already accustomed to looking for MedicAlert pendants, we could have the word 'Deafblind' engraved on the pendant and the contact phone number for the EISP.

- first responders typically arrive at the scene of an emergency prior to an intervenor being dispatched and arriving to assist. This is a critical time as first responders need to gather essential information and they are often confused as to how to assist and communicate with the individual who is Deafblind.
  - Solution: Create an Emergency Communication Kit which includes various communication aids and the contact information for the Emergency Intervenor Service.
- intervenors who work for CNIB DBCS are not contracted to be on-call, and CNIB did not support the idea of staff being placed on-call with this new emergency service. So, how will we ensure intervenors will be willing to take emergency assignments after-hours and over weekends?
  - Solution 1: offer intervenors a higher rate of pay as compensation for working in emergency settings and pay them an additional call-out fee as a way of compensating them for dropping whatever they were doing to respond to the request. This rate of pay would be almost double what they would make during a non-emergency assignment. Note: After a review of the service was conducted in 2015, the idea of staff being on-call was reconsidered but was still seen as an unnecessary expense and an unnecessary responsibility or stress for staff considering the low rate of emergency requests per region/per month.
  - Solution 2: provide intervenors with an emergency work kit,

so they would be ready to respond to an emergency.

MCSS supported the proposal in it's entirety, so the next step was implantation.

- A training video was created featuring members of the Deafblind community, paramedics, police and emergency room nurses who were willing to act in the videos.
- EISP brochures and posters were created
- Items were created to assist with the identification of a person as being Deafblind, these included;
  - a snap-on cover which fits over or attaches to a person's health card. This snap-on cover indicates that the person has vision loss and hearing loss and lists the phone number for the CNIB EISP. Even if the person is unconscious, a first responder in attempting to identify the person, would see this information on the person's health card.
  - communication alert cards; these cards are personalized and state the person's vision and hearing loss i.e. "I am Deaf and have no vision" and lists the communication method the person uses (e.g. "I use tactile American Sign Language and can not read print"). It also states, "I require an intervenor to facilitate communication. Please contact..."
- MCSS agreed to pay for MedicAlert membership and pendants. People can contact the coordinator of the EISP to arrange for purchasing a membership and pendant.
- An emergency communication kit was created. This kit contains;
  - a pad of paper with a black marker (only included if the person has residual vision)
  - an emergency communication book – this book uses graphic

images which are easy to understand. The first responder simply points to an image (question) they want to ask, and the person can respond. This book is available in standard size, large print and with braille overlay. The book was created in consultation with paramedics. Therefore, it is user-friendly as the images (questions) are listed in the order a paramedic has been trained to ask them.

- a visor or hat – this can be used if the person is having difficulty seeing due to glare (e.g. they may be laying down on a stretcher and have lights shining which inhibits their ability to see what people are doing/saying).
- a key tag – people are encouraged to attach this to their home keys. They can then show anyone the key tag when they want to request an emergency intervenor as the key tag has the name of the program and the contact information.
- stickers – state that the person has vision loss and hearing loss, the phone number for the EISP and the general helpline for CNIB, if the request is not an emergency. These stickers can be used for multiple purposes.
- business cards with braille
- brochures in English and French
- instruction sheets are included to explain each item. People are also encouraged to add items to the kits, i.e. a magnifier, old pair of glasses, list of medications, emergency contact information, non-perishable food, coins, etc.
- MCSS supported the proposed budget, which included the higher rate of pay for intervenors who work emergency assignments. A call-out fee was also supported.
- Intervenor work kits were created. These kits include;
  - pad of paper and black markers
  - first aid kit with gloves

- business cards
- brochures
- EISP work shirt; this shirt is black (or white) and has the EISP logo on the sleeve. This shirt can be thrown on overtop of any clothing (e.g. if an intervenor was called in for an emergency and they had a bright coloured tank top on. Not only does it help with the visual needs of the person, it also helps identify them as a professional intervenor versus a family member or friend.
- intervenor work verification forms; intervenors fill in these forms after an assignment and submit them to their manager and to the EISP coordinator.
- intervenors are encouraged to add any other items to their kits (e.g. money for parking, sweater, non-perishable food, bottle of water, etc.)

From there, a system was set up to support the 24 hour/7 days/week program.

1. A project lead was hired to oversee the operations of the EISP with support from the management team.
2. A call centre was hired to facilitate the incoming requests. Requests could be made by phone, TTY, text messaging or email.
3. The project lead sent out registration forms to the clients and staff to create a database. The call centre could then use this database to;
  - a. find pertinent information about the person requesting the intervenor (e.g. the person's communication method, their preferred intervenors (if listed), whether they were a guide dog user and who to contact if their dog needed to be taken care of, any vital information the person had included on their registration form. Registration

was not mandatory, but strongly encouraged.

- b. find contact information for the intervenors to dispatch someone to assist. The call centre was instructed to follow the person's preference list of intervenors the client felt most comfortable working with, especially in an emergency. CNIB DBCS provided other intervenor options so the call centre had at least three to five names to contact. If none of those intervenors were available or responding, the call centre went through the database to locate other intervenors who lived in the region who were comfortable working with someone using a particular communication method. An interactive map was also added as a resource to locate intervenors in the region. Intervenor hours are paid out at the higher rate of pay and not tracked as overtime. Note: Intervenor are not on-call. If an intervenor receives a call to assist, they have the option of accepting the assignment or declining (e.g. they have young children, and no one is available to help out, or they are out of town, etc.). The call centre would then proceed to the next intervenor. If no intervenor was found, the call centre would contact the project lead for the EISP about next steps.
4. The project lead would receive an email notification immediately after a request was received. This notification would then be forwarded to the managers. Also, a detailed report about the request would be sent the following morning to the project lead who could review and document the information for statistical purposes and would follow up on any issues.

<sup>6</sup> www.medicalalert.com



### Successes and ongoing challenges

The Emergency Intervenor Service is responding to an average of eight emergency requests per month. Budgeting for an emergency service is difficult, as emergencies are not predictable or planned. Having said that, over the last four years, we have seen a consistent number of calls coming in. That doesn't mean these numbers won't fluctuate, but it helps with anticipating an accurate budget. Also, the number of requests may increase as the clients become more aware of the service and recognize the availability of intervenors is now 24/7 (e.g. people are accustomed to waiting for an intervenor to arrive before dealing with a health issue and may need a reminder that this is no longer necessary as they can contact the EISP anytime).

One of the first emergency calls the program received was a request for an intervenor to assist at a hospital emergency room, as a person who was Deafblind was hit by a vehicle. Immediately, we saw the results of having this formal system in place. This individual was able to show the paramedics their health card, which had the snap-on cover indicating the EISP contact information, and an intervenor was dispatched. The paramedics, upon reading the cover, knew this person had vision loss and hearing loss.

Approximately 50 per cent of CNIB's DBCS clients have registered for the EISP; around 60 per cent have received their free emergency communication kit. This percentage generally reflects those individuals who receive regular intervenor service because they're in constant contact with intervenors. For those who have not registered or who have not shown interest in the emergency communication kits, as some feel they don't need the service, (e.g. they are young and don't feel it's applicable to them at this time, or they might not

be using intervenor services yet and are accustomed to having a family member assist them).

There continues to be challenges with promoting the EISP, the needs of the Deafblind community and the role of an intervenor, particularly with hospitals, given the size. We have attempted to deal with this by; promoting self-advocacy within the Deafblind community, offering awareness training to hospital emergency room staff, paramedics, police and firefighters, reaching out to college programs that teach paramedics, nurses, police and firefighters, tapping into training platforms that paramedics, nurses, police and firefighters already use, and promoting awareness on CNIB DBCS' website and social media channels, including Facebook and YouTube.

We have had ongoing issues with the call centre we have hired. There have been incidents where a text message or email request has not been acknowledged or followed up, or a call centre staff are not following the written instructions and depend on the project lead for the EISP to solve problems that are clearly identified in the support materials and script that the staff member has on file. The staff turnover and/or unfamiliarity of the EISP account has led to some of this confusion. The call centre handles multiple accounts and operators (particularly those working late night shifts or weekend shifts) are unfamiliar with the EISP service, so they're not using the information sheets posted on the account.

We have had to deal with non-compliance issues, (e.g. a person emails the project lead for the EISP to report they were in the hospital over the weekend and showed the various items listing the EISP contact information but were told the service wasn't necessary). In another scenario, the person showed their identification as being Deafblind, showed

the contact information for the EISP and assumed the nurse was contacting the EISP. The person sat there waiting for an intervenor to arrive. At first, the person assumed that an intervenor was not available, but found out later that the request wasn't documented with the EISP call centre and no call had been made.

In Ontario, we have the Accessibility for Ontarians with Disabilities Act (AODA). This legislation highlights a person's right to have an intervenor. AODA training is mandatory for all businesses, small and large. This is great, in theory. Unfortunately, there are issues with enforcement. Hopefully, this will change in the near future.

### Next Steps

The CNIB EISP will continue to monitor the effectiveness of the program and solicit feedback from all stakeholders.

After the first year of operation, a one-year external review was conducted. Recommendations in this review included: enhanced awareness efforts; ongoing training for intervenors, clients and call centre staff; increased awareness as to what qualifies as an emergency and improved efficiency with the call centre, etc.

We will continue to work towards meeting the recommendations outlined in that review and look forward to potential partnerships with other intervenor service providers in the hopes of either expanding this program or working in collaboration to ensure that all Ontarians who are Deafblind receive intervenor support in an emergency.

**For more information contact Janine Tucker, CNIB Deafblind Services (Janine.tucker@deafblindservices.ca)**

# An Analysis of the Social Return on Investment (SROI) for the Lega del Filo d'Oro

Clodia Vurro<sup>1</sup>, Stefano Romito<sup>2</sup> and Patrizia Ceccarani<sup>3</sup>

**The Lega del Filo d'Oro<sup>4</sup> is an Italian non-profit organization working for people with multi-sensorial impairments. Its mission is to provide various services for deafblind and multisensory impaired individuals, including education, rehabilitation, as well as supporting their integration into the family and society.**

**I**n collaboration with the Department of Economics, Management and Quantitative Methods of the University of Milano and Vita Media Company, the Lega del Filo d'Oro undertook an analysis of social return on investment (SROI) analysis of its intervention model, with the aim of providing a monetary evaluation of the social value created for their clients, their families, and the communities in which the organization is located.

The results of the pilot project were released in April 2018 to explain the social value generated by Lega del Filo d'Oro in Osimo (Marche Region)<sup>5</sup> Italy for the period 2014–2016. A similar analysis will be undertaken for the entire organization in Italy in the near future.

### The SROI analysis: A methodological overview

Building on recent advancements in the field of measuring the effectiveness of nonprofits, a SROI analysis was developed with the intention of producing a quantitative and monetary description of the social value from a social intervention model. Social value creation refers to the ability of an institution, organization or individual to produce a tangible, durable change resulting from a certain set of actions in a given field of intervention. A SROI analysis quantifies the difference made to specific stakeholders of a non-profit organization (NPO, hereafter). In this way, NPOs can strengthen their reporting with a more positive and transparent communication about how resources have been used

to achieve results. Furthermore, they are useful for recommending changes in procedures for employees and volunteers to make better use of resources.

A SROI analysis is guided by the following principles:

- Involvement of stakeholders who have a 'stake' or an interest in the subject
- Ensuring stakeholders understand what changes might occur
- Include only what is material in the process
- Being transparent with the stakeholders showing what will be reported
- Being conservative when evaluating the impacts ie not overclaiming
- Verifying of the results with independent observers

**“Social value creation refers to the ability of an institution, organization or individual to produce a tangible, durable change resulting from a certain set of actions in a given field of intervention.”**

<sup>1</sup> University of Milan, Italy ([www.unimi.it/ENG/](http://www.unimi.it/ENG/))

<sup>2</sup> Bocconi University, Milan, Italy (<https://www.unibocconi.eu>)

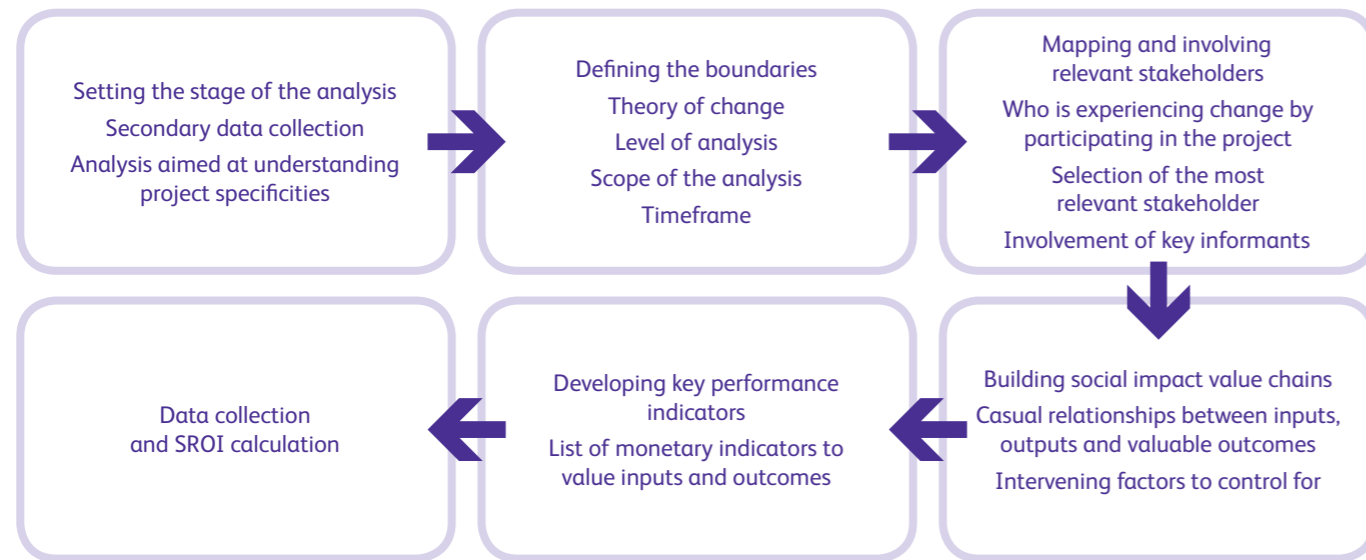
<sup>3</sup> Lega del Filo d'Oro

<sup>4</sup> The Lega del Filo d'Oro ([www.legodelfilodoro.it](http://www.legodelfilodoro.it)) is a large corporate member of DbI

<sup>5</sup> Vurro, C. Romito, S., 2018, La valutazione economica degli impatti sociali della Lega del Filo d'Oro: Un'analisi SROI, Milan: VITA.

For an organization to perform a SROI analysis, the following steps need to be followed as shown in Figure 1.

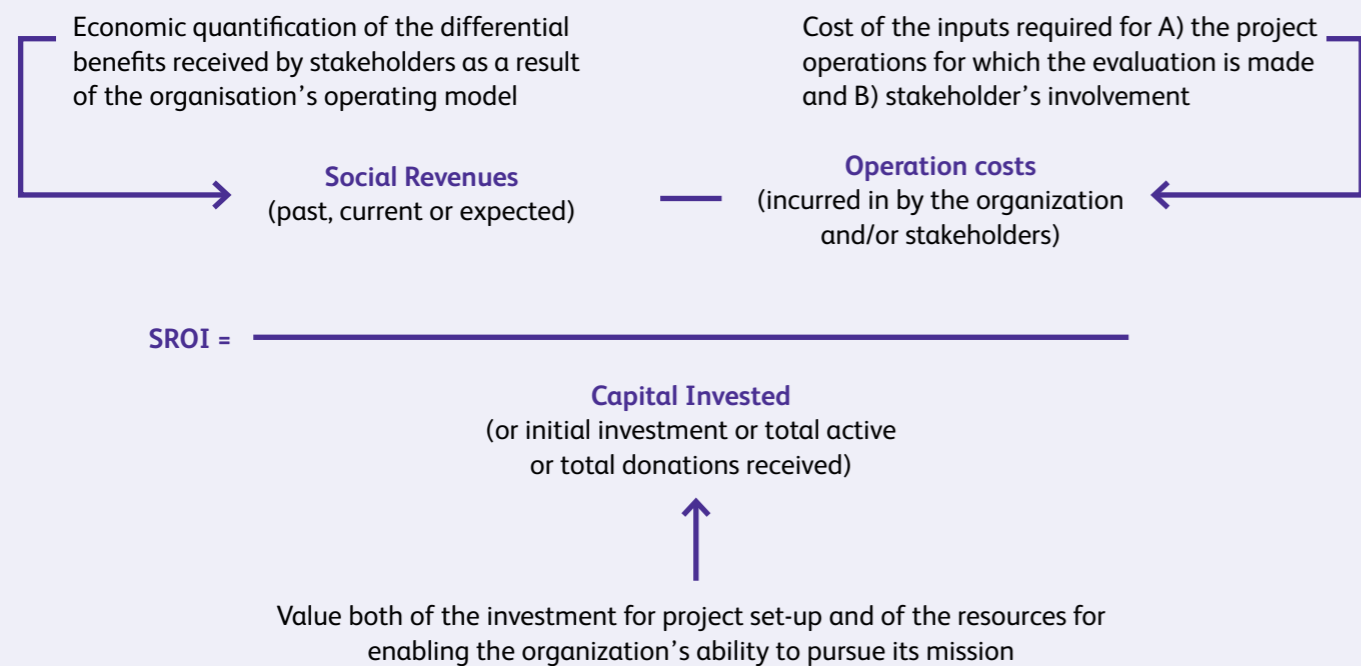
FIGURE 1: A process-based view of the SROI analysis



Source: Personal elaboration

A SROI calculation measures the value of net social benefits created by an organization in relation to their investments together with those from other supporting stakeholders to better achieve the benefits (Figure 2) for its stakeholders).

FIGURE 2: SROI CALCULATION



Source: Personal elaboration

The result from a SROI calculation is measured as a ratio of monetized social value. For example, a ratio of 1:3 indicates that an investment of euro 1 delivers 3 euros of social value.

**Application of the SROI methodology to Lega del Filo d’Oro**

In accordance with the SROI principles and methodology, the project identified the primary stakeholder in this process as being the disabled individuals themselves, including their family members, employees, volunteers and the local community in which they all live. Together all the stakeholders can be said to benefit from, and contribute to, the realization of the social mission of the Lega del Filo d’Oro.

The next step was to identify all activities and their impacts, based on in-depth consultation with key participants (e.g., parent association representatives, medical doctors, staff and members of the management team). As a result, social values were developed for each stakeholder category.

The results of the input to output to outcome evaluation shows that the intervention model provided by the Lega del Filo d’Oro, including its’ multidisciplinary evaluation, educational and rehabilitation services, has direct benefits for these multi-disabled individuals and their families. As a result of these services, the individuals are able to demonstrate an improved ability to manage their complex disability and experience reduced social isolation through gaining better access to society. The individuals are more able to access a broad level of community services. Furthermore, the lives of their families have also been positively affected by the supports offered by Lega del Filo d’Oro. This includes being able to return to the working lives as well as being better able to partake in personal leisurely activities.

Primary data was collected from a sample of 99 families to provide monetary information based on the areas identified above. Secondary data was collected to quantify and evaluate the impact of the Lega del Filo d’Oro services on employees,

volunteers and the local community at large. Types of evaluations included the value of professional training received by employees and volunteers, as well as employment created by the Lega del Filo d’Oro in the Marche Region.

Other impacts evaluated included: an increased level of community volunteerism; the value of the knowledge transferred to local institutions and organizations related to the social inclusion of deafblind and multisensory impaired, and the overall increase in the volume of economic activities in the regional area.

**Results of the SROI analysis**

For every Euro invested in the projects of the Lega del Filo d’Oro by public sector health institutions and donors, the value of the average annual social return, i.e. the change generated in the lives of the beneficiaries and their families, volunteers, employees and the Region of Marche as a whole is equal to **1.93 euros** of delivered social value (average annual SROI ratio 1:1.93). Over the three-year period of the analysis, the Lega del Filo d’Oro has created 17.5 million euros a year in social value, recording a constant increase of about 15 % (from 16,629,605 Euros in 2014 to 18,854,423 Euros in 2016).

In 2016, Lega del Filo d’Oro generated a social value of about 1 million euros for families. This accounted for parents returning to work, becoming themselves more involved in social life, having more

financial resources due to reducing the hours of counselling and family therapy they used to pay for, etc. A further 1.2 million euros in social value has been created by the highly skilled personnel and volunteers supported by Lega del Filo d’Oro who now operate in schools and various local services.

Education, Staff Training and sharing knowledge are essential in the search for innovative and effective solutions to respond to these disabled individuals with complex disabilities. Lega del Filo d’Oro offers a unique opportunity for staff and volunteers to acquire, develop and implement specialized skills. This is done through classroom and on the job training.

For delivering the services to the beneficiary clients and their families, the Lega del Filo d’Oro engages a large number of professionals per client. For example, the Diagnostic Center has a ratio of 2.7:1, well at above regional regulation standard. In terms of social value, this higher ratio translates into 5.7 million euros of additional salaries paid in 2016 alone.

Finally, Lega del Filo d’Oro has contributed significantly to the economy of the local communities and the surrounding areas in which it operates. On average, 9.3 million euros per year is the value of additional economic activity created by the Lega del Filo d’Oro.

This SROI analysis has demonstrated the possibility for Lega del Filo d’Oro to move away from its emphasis on costs for

*“Beyond measuring results, this research project has showed the feasibility of applying such a methodology even in multi-faceted complex contexts, such as that in the area of severe disabilities.”*



users and treatments towards the value created for local stakeholders, emphasizing the areas of impact that are not necessarily visible from the outside. The results show how the entire context, in which Lega del Filo d'Oro operates, benefits from its existence. In other words, the multisensory disabled individuals and their families are not the only beneficiaries of Lega del Filo d'Oro,

despite their being its *raison d'être*. The employees and volunteers who provide the essential hands-on support, also benefit through their professional growth and the acquisition of skills they could rarely obtain elsewhere.

This pilot project has offered insights into the methodological and procedural aspects of quantifying the impact of the intervention

model for working with deafblind and multisensory impaired individuals. Key issues explored included: the monetary quantification of benefits in areas where qualitative measures prevail. Beyond measuring results, this research project has showed the feasibility of applying such a methodology even in multi-faceted complex contexts, such as that in the area of severe disabilities.

For more information, contact: Patrizia Ceccarani (ceccarani.p@legadelfilodoro.it)



## COME AGAIN! HOW TO PLAN A HOLISTIC REHABILITATION PROCESS

*CFD's deafblind counsellors provide specialized advice and support to persons with acquired deafblindness, that is, persons who develop severe combined hearing and visual impairment during the course of their life. A recently completed project has aimed to develop a coherent and holistic rehabilitation course for this target group. The first in a series of three, this article describes the project's theoretical framework*

Acquired deafblindness has wide-ranging consequences for the person's overall life situation. Among the main challenges, it presents obstacles to communication, access to information and independent travel. It increases the risk of loneliness and isolation, and persons with deafblindness have a higher prevalence of both psychological and physical health issues.

### AN ARDUOUS AND LONELY EFFORT

A change in life conditions as profound as a severe, or perhaps even complete, loss of vision and hearing initiates a process that transforms the person's life completely. This process is an arduous and lonely effort that is often unseen and unrecognized.

Outside support can have a significant impact on the course and outcome of this process. The purpose

of the project has been to develop a coherent and holistic rehabilitation course for persons with acquired deafblindness, with a focus on the life adjustment process.

### A DOCUMENTED NEED

Such a coherent rehabilitation course for people with deafblindness does not currently exist. However, the need for it is apparent. A Scandinavian research project about life adjustment<sup>1</sup> found that the support a person receives during the process of adjusting to a life with deafblindness has a significant impact on the course and outcome of the process. Specifically, the deafblind participants in the study expressed a need for a coordinated approach that addresses all aspects of living with deafblindness – with particular emphasis on the psychological aspects in regard to adjusting one's self-image and identity.

A previous project at CFD, funded by Helsefonden (The Danish Health Foundation), aimed to identify individuals with Usher syndrome, type 2<sup>2</sup>. In this study, participants with deafblindness stated in focus groups interviews that they lacked follow-up psychosocial and personal support.

Further, a study conducted by Örebro University found a higher prevalence of mental health issues, not least suicidal ideation and attempted suicide, among persons with deafblindness compared to persons without deafblindness<sup>3</sup>.

### PRACTICAL TOOLS AND STRATEGIES

These and other studies document the need for a rehabilitation course aimed at giving the participants practical tools and strategies to facilitate their life adjustment process.

In 2015, CFD Rådgivning therefore applied for a grant of DKK 2 million from the Danish government fund Satspuljen for a project aimed at developing such a course.

So far, two pilot rehabilitation courses have been held as part of this project – one aimed at persons with deafblindness who use sign language and one aimed at persons with deafblindness who use speech.

The two experienced deafblind counsellors Kirsten Washuus and Else-Marie Jensen, who were in charge of the project, comment on this distinction in terms of target groups:

'It is crucial for the participants to feel at ease during the courses. To ensure that, we decided from the outset that we would establish

separate courses for the two groups. Although they have deafblindness in common, their life situations are often quite different, depending on their language.'

They add, 'Above all, deafblindness is a communication impairment, which means that it takes a very particular focus and careful planning to create the right conditions for communication. It was essential to ensure that the participants could communicate directly with each other within the group. However, despite differences between the two groups, throughout the project we have also found many similarities when it comes to the experience of adjusting to a new life.'

### THREE MODULES = THREE HOUSES

Each course consisted of three modules, focused in turn on vision and hearing, personal energy and networks. In the project terminology, the themes were metaphorically introduced as three separate houses, which the participants visited: the AV House (concerning audio-visual aspects, that is, hearing and vision), the Energy House and the Network House.

The three general themes were chosen because they were considered essential for a person with deafblindness.

Kirsten Washuus explains: 'The reason why these particular themes are essential is that together, they cover the entire life situation for a person with deafblindness. The purpose of the project was to develop a holistic approach, and we found that the topics that were included in the three themes allowed us to address the person's life in full.'

### THREE MODULES = THREE HOUSES

**AV House:** about hearing and vision and the participants' own experiences of hearing and vision loss

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

**Network House:** about communication and relationships with family, co-workers, friends and others members of the network

**"IT IS CRUCIAL FOR THE PARTICIPANTS TO FEEL AT EASE DURING THE COURSES. TO ENSURE THAT, WE DECIDED FROM THE OUTSET THAT WE WOULD ESTABLISH SEPARATE COURSES FOR THE TWO GROUPS. ALTHOUGH THEY HAVE DEAFBLINDNESS IN COMMON, THEIR LIFE SITUATIONS ARE OFTEN QUITE DIFFERENT, DEPENDING ON THEIR LANGUAGE."**

### THE LIFE ADJUSTMENT MODEL AS THEORETICAL FRAMEWORK

As its theoretical framework the project relied on the so-called life adjustment model.

The model was originally developed by Ann-Christin Gullacksen at Malmö University, intended initially for persons with chronic illness and later expanded to be used with persons with a hearing impairment.

Over the past ten years, the model has seen increasing use in the field of deafblindness, initially thanks to a Scandinavian research project in 2008-2011. One of the outcomes of the project was the book 'LIFE ADJUSTMENT and Combined Visual and Hearing Disability/Deafblindness – an Internal Process over Time'.<sup>4</sup>

The Danish representative in the project was Anette Rud Jørgensen, who was a deafblindness counsellor at the time. Today she is the manager of the national deafblindness counselling service.

### THE LIFE ADJUSTMENT PROCESS

The life adjustment model describes the process people go through when they acquire a sensory impairment, such as deafblindness. The model identifies three stages in the adjustment process:

- Holding on
- Processing/exploring
- Rooted in oneself



**HOLDING ON**

The initial stage, Holding on, begins when the person first experiences changes in their vision and/or hearing. The initial reaction may include denial of the new situation, as the person instead tries to hold on to what has worked so far, and what they are accustomed to. Towards the end of this stage, there is a growing recognition that life cannot continue exactly as before, and that the future is going to look different than one had imagined. That can lead to an emotional crisis that may continue well into the subsequent stage.

**PROCESSING AND EXPLORING**

The second stage, Processing and Exploring, supersedes the initial stage when people have reached some degree of recognition of their changing life conditions. During this stage, they begin to address the new situation, process how they relate to deafblindness and explore themselves and deafblindness in relation to the environment. The stage may be prolonged and exhausting, and it may involve strong emotional reactions and a feeling of loss. Towards the end

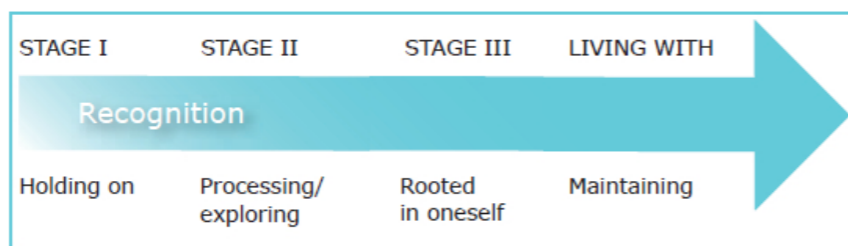
of the stage, however, people begin to acknowledge the consequences of deafblindness and accept that it is possible to live with them.

**ROOTED IN ONESELF**

By the time they reach this stage, people have rediscovered the core of their identity and integrated the term of deafblindness into their life situation. They have healed their life and become whole again. Many of the experiences they have made during the process now have to be embraced as a fact of life. They begin to move on, after reshaping their identity and self-image. With regard to rehabilitation, at this stage people often begin to be able to benefit more from technical aids and professional support, for example from interpreters and a dedicated contact person.

**MAINTAINING**

After going through these three stages, people now move on to living with deafblindness. This is not a finite process but a continuous maintenance effort that involves ongoing adjustments over the coming years, as their vision and hearing continue to change. Maintenance includes continued contact with professionals, ongoing use of assistive aids – and the acquisition of new ones – and a growing awareness of the need to use one's energy wisely by planning and prioritizing activities.



The life adjustment model (illustration used with the kind permission of the Nordic Centre for Welfare and Social Issues)



**MEET TWO OF THE PARTICIPANTS BEFORE AND AFTER THE COURSES**



LUKE



LINDA

**KNOWING THE STAGE CAN BE CRUCIAL**

Commenting on the choice of the life adjustment model as the framework for the rehabilitation courses, Kirsten Washuus says,

‘We know that it can be crucial for professionals to know what stage in the overall process the person is at. If we offer deafblindness-specific support or assistive aids at a time when the person is still trying to hold on to or restore what once was, we are going to miss the mark. The kind of rehabilitation course we offer in this project is based on the premise that the person has completed stage one and is thus at a stage where they are motivated to receive support with processing and exploring new strategies for managing everyday life.’

**THE PSYCHOLOGICAL ASPECT IS A CONSISTENT CONSIDERATION**

From the outset, it was a key goal of the project to include a psychological perspective throughout. This task was shared between practising psychologist Jette Fischer and CFD’s in-house psychologist Marianne Rosenstand Bjåstad (who is herself a sign language user).

Persons with deafblindness need psychological support to learn to live with deafblindness. That became evident, for example, in the project

mentioned above aimed at identifying individuals with Usher, type 2.

Jette Fischer has no doubt that this constitutes a key aspect of the rehabilitation process.

‘It is important to address and manage all the emotions and the state the persons can get into, with fixed self-perceptions, challenges to their self-esteem, fatigue and so forth. We have to help people acknowledge and understand these issues, so they can find ways to act in their new situation,’ says Jette Fischer.

**SMART GOALS AND FOUR OBJECTIVES**

The overall goal was that at the conclusion of the project, more than 75% of the participants were to have achieved two goals.

- The participants were to have
- initiated new activities in or outside the home
  - established new relationships (expanded their network)

For the individual participants, these goals were stated within the framework of the SMART model (see fact box). The outcome was that 80 to 100% of the participants in the courses achieved their SMART goals.





**THE SMART MODEL**

In the SMART model each objective has to be stated in a way that is

- Specific
- Measurable
- Achievable
- Relevant
- Time-bound (attainable within a certain time frame).

Another four objectives were stated for the participants in the rehabilitation courses.

First, the individual participants should achieve increased insight into their own situation and needs, including a better understanding of their own vision and hearing function and greater awareness of the compound effect of combined vision and hearing loss.

Second, they should find that their ability to process this demanding life adjustment process had been made easier by the exchange of experiences with other course participants and the psychological support.

Third, they should feel better able to engage with the outside world thanks to compensatory techniques and assistive aids that facilitate their communication, access information and wayfinding.

Fourth, they should acquire coping strategies for managing stress. Deafblindness often makes communication and independent travel very taxing and potentially stressful tasks. Hence, the participants should acquire strategies for how to prioritize their energy and activities.

As one participant put it, 'I have become very conscious of enjoying those little moments. And I am better at taking care of myself. There's still a lot of work to do, but I have become very conscious of the benefits of taking a timeout.'

If you would like to learn more about the project, please contact Kirsten Washuus at kw@cfid.dk.

**PROJECT FACTS**

Project coordination is handled by CFID.

The project runs from October 2015 through April 2018.

It is funded by a grant of just under DKK 2 million from the Danish government fund Satspuljen.

A total of 11 persons with deafblindness took part in the two rehabilitation courses that were included in the project.

The courses were structured as three three-day modules.

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2. See more (in Danish) in the article *Vi bliver ført nye veje...* at www.cfid.dk.
3. Health and People with Usher Syndrome, Wahlqvist M, Örebro University 2015.
4. See note 1.

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**Management Committee**

The Management Committee for the 2015–2019 period includes the two elected offices: President and two Vice-Presidents, Immediate Past President, Treasurer, Information Officer, Secretary, Development Officer, Strategic Planning Officer, Network Coordinator and Diversity Officer.



**Gillian Morbey**  
President  
Sense  
UK  
(Gillian.Morbey@sense.org.uk)



**Bernadette Kappen**  
Vice-President  
The New York Institute  
for Special Education  
USA  
(bkappen@nyise.org)



**Frank Kat**  
Vice-President  
NETHERLANDS  
(F.Kat@outlook.com)



**William Green**  
Immediate Past President  
AUSTRIA  
(green.lfo@usa.net)



**Gary Daly**  
Secretary  
Able Australia  
AUSTRALIA  
(gary.daly@ableaustralia.org.au)



**Maria Brons**  
Joint Treasurer  
Kentalis  
NETHERLANDS  
(m.brons@kentalis.nl)



**Knut Johansen**  
Development Officer  
Signo Vivo  
NORWAY  
(knut.johansen@signo.no)



**Carolyn Monaco**  
Strategic Planning Officer  
Canadian Deafblind Association  
CANADA  
(carolyn.monaco@sympatico.ca)



**Trees vanNunen**  
Joint Treasurer  
Kentalis  
NETHERLANDS  
(t.vanNunen@kentalis.nl)

**Board Observers**

DbI's partner organizations, ICEVI and WFDB have observer status on the DbI Board:  
International Council for Education of People with Visual Impairment

Frances Gentle  
(frances.gentle@ridbc.org.au)  
www.icevi.org  
World Federation of the Deafblind  
Geir Jensen  
(geir.jensen@fndb.no)  
www.wfdb.eu



**Stan Munroe**  
Information Officer  
Canadian Deafblind Association CANADA  
(information@deafblindinternational.org)

## Representing Large Corporate Members



**Gillian Morbey**  
Sense  
UK  
(Gillian.Morbey@  
sense.org.uk)



**Matthew Wittorff**  
Senses Australia  
AUSTRALIA  
(matthew.wittorff@  
senses.org.au)



**Sian Tesni**  
CBM (Christoffel  
Blindenmission)  
UK  
(sian.tesni@  
cbm.org.uk)



**Andy Kerr**  
Sense Scotland  
UK  
(akerr@sense  
scotland.org.uk)



**Cathy Proll**  
Canadian Deafblind  
Association  
Ontario Chapter  
CANADA  
(cproll@cdba  
ontario.com)



**Maria Brons**  
NETHERLANDS  
(m.brons@  
kentalis.nl)



**Kate MacRae**  
Able Australia  
AUSTRALIA  
(kate.macrae@  
ableaustralia.org.au)



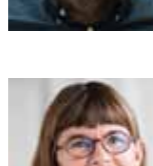
**Eugenio Romero Rey**  
ONCE  
SPAIN  
(err@once.es)



**Roland Flaig**  
German Deafblind  
Consortium  
GERMANY  
(roland.flraig@  
stiftung-st-  
franziskus.de)



**Marianne Riggio**  
Perkins International  
USA  
(marianne.riggio@  
perkins.org)



**Lena Goransson**  
National Resource  
Centre for  
Deafblindness  
SWEDEN  
(lena.goransson@  
nkcdb.se)



**Roxanna  
Spruyt-Rocks**  
DeafBlind  
Ontario Services  
CANADA  
(ceo@deafblind  
ontario.com)



**Rossano Bartoli**  
Lega del Filo  
d'Oro  
ITALY  
(info@legadelfilo  
doro.it)

## Representing DbI Networks



**Andrea Wanka**  
CHARGE Network  
Stiftung St. Franziskus,  
Heiligenbronn  
GERMANY  
(aw@andrea-  
wanka.de)



**Ricard Lopez**  
European  
Deafblind Network  
SPAIN  
(fecoce@fecoce.org)



**Emma Boswell**  
Usher Network  
UK  
(Emma.Boswell@  
sense.org.uk)



**Joe Gibson**  
Outdoor Network  
NORWAY  
(deafblindoutdoors  
@gmail.com)



**Simon Allison**  
Youth Network  
UK  
(simon.allison@  
sense.org.uk)

## Representing Small Corporate Members



**Carolyn Monaco**  
Canadian Deafblind  
Association  
CANADA  
(carolyn.monaco@  
sympatico.ca)



**Marleen Janssen**  
University of  
Groningen  
NETHERLANDS  
(h.j.m.janssen@  
rug.nl)



**Ricard Lopez**  
Spanish Federation  
of Deafblindness  
(FESOCE)  
SPAIN  
(rlopez@  
sordoceguera.com;  
fesoce@fesoce.org)



**Gloria Rodriguez-Gil**  
Latin America and  
the Caribbean  
Perkins International  
ARGENTINA  
(gloria.rodriguez@  
perkins.org)



**Jackie Brennan**  
Overbrook School for  
the Blind  
USA  
(jackie@obs.org)



**Ursula Heinemann**  
Österreichs Hilfswerk  
für Taubblinde  
AUSTRIA  
(ursiheinemann@  
usa.net)



**David Murray**  
Deafblind Australia  
AUSTRALIA  
(david.murray@  
deafblind.org.au)



**Knut Johansen**  
Signo  
Døvblindesenter  
NORWAY  
(knut.johansen@  
signo.no)



**Bernadette Kappen**  
The New York  
Institute for  
Special Education  
USA  
(bkappen@  
nyise.org)



**Lars Sobje**  
Center for  
Deafblindness and  
Hearing Loss  
DENMARK  
(laejs@rn.dk)



**Koh Poh Kwang**  
Lighthouse School  
SINGAPORE  
(kohpohkwang@  
lighthouse.edu.sg)



**Marie-Jose  
vandenDriessche**  
Royal Dutch Visio  
NETHERLANDS  
(MarieJosevan den  
Driessche@visio.org)



**Trish Wetton**  
Forsight Australia  
AUSTRALIA  
(trish.wetton@  
forsight.net.au)



**Maria Creutz**  
Nordic Centre  
for Welfare and  
Social Issues  
SWEDEN  
(maria.creutz@  
nordicwelfare.org)



**Mirko Baur**  
Tanne, Stiftung  
für Taubblinde  
SWITZERLAND  
(mirko.baur@  
tanne.ch)



**Lena Goransson**  
National Resource  
Centre for  
Deafblindness  
SWEDEN  
(lena.goransson@  
nkcdb.se)



## It is up to YOU!

### Who will Take the Leadership for DBI in the Period 2019 – 2023?

**Are you, or someone you know, interested to take on one of these officer's roles? We are seeking dedicated and passionate persons who can take the lead in the further development of DbI, those who are willing and able to work in close collaboration with families, professionals and persons with deafblindness from around the world.**

#### WHO WILL HAVE A SEAT ON THE BOARD?

By serving on the Board, Corporate members and Networks have a great opportunity to lead DbI into the future, by taking on the responsibility of managing the association.

#### 2018: NOMINATIONS YEAR

The DbI Nominations Committee urge you to have your say and take part in the process towards the election of the future President, Vice-President (2) and Board members of DbI, to be ratified during the Annual General Meeting in the upcoming DbI World Conference in Australia's Gold Coast, August 12–16, 2019.

The first call for nominations should have reached all members by now, and we hope you take the opportunity to make sure there will be a solid and dedicated leadership within DbI also in the next period.

#### GUIDELINES FOR NOMINATIONS

When you consider your nominations for President and Vice-Presidents, please have these guidelines in mind:

1. The person you are nominating must be able to be unifying and demonstrate fairness and honesty. The President and Vice-Presidents cannot self-nominate.
2. The nominated person needs to be a good communicator and be able to represent DbI at the highest level.
3. A nominated Vice-President should be willing and able to stand in for the President, if necessary.

When you consider nominations for the Board, please have these guidelines in mind:

1. The Board consists of Corporates and Networks. Self-nomination to the Board is acceptable. The nominated Corporate must be a paid-up 2018 member of DbI. The same applies to representatives for Networks.
2. The nominated corporate/network must have a representative who is willing to stand.
3. The representative should have the resources and capacity to attend meetings.

The nominees must have the best interests of DbI at heart and approach the work in a positive and honest way.

The Nominations Committee is seeking as wide a representation as possible for the Board. The Board will be composed of a President, 2 Vice-Presidents, the immediate Past-President, and no more than 35 other members. No more than 15 members of the Board can be large corporate members. This means that there will be up to 20 seats available for small corporates and networks. The function time for Board members is 4 years.

#### 2019: ELECTION YEAR

An electronic ballot decides who will be President and Vice-Presidents. When the nominations process is over by the end of November 2018, all members who have the right to cast a vote will receive information on the voting process. This electronic ballot takes place from February to April 2019.

Note that you are required to pay your DbI membership fee for 2019 by March 2019, for your vote to be accepted.

Nominees for President and Vice-President will receive immediate information of the outcome.

Nominated Board members will receive information of the Nominations Committee's proposal no later than April 2019. The Annual General Meeting appoints the new Board during the World Conference in August 2019.

**Any questions concerning nominations – send it to [dbinominations@obs.org](mailto:dbinominations@obs.org)**

#### THE NOMINATIONS COMMITTEE:

Jackie Brennan, USA (Chair)  
Emma Kulombe, Malawi  
Ricard Lopez, Spain  
Graciela Ferioli, Argentina  
Knut Johansen, Norway (ManCom member)

## Secretariat News

Since the last DbI Review, DbI ManCom met in April in Hyannis on Cape Cod, USA for our bi-annual meeting and to attend the DbI Network of the America's Conference.

As an organization, we continue to work on the Diversity within DbI and have been guided in this initiative by both Dennis Lolli and Graciela Ferioli.

The DbI Nominations Committee has been set up after the DbI Board approved the current members which include:

- Jackie Brennan, USA (Chair)
- Emma Kulombe, Malawi
- Ricard Lopez, Spain
- Graciela Ferioli, Argentina
- Knut Johansen, Norway (DbI ManCom member)

The Nominations Committee is active setting up the process for the next elections for DbI Board which will take place in 2019.

#### Conferences

As DbI Secretariat and the Conference Coordinator of the 17th DbI World Conference 2019 in Australia, I have had the pleasure of speaking at conferences in India, USA, Switzerland and Spain. I had the pleasure of being Chair of the World Federation for the Deafblind (WFDB) General Assembly in Benidorm, Spain. DbI has a Memorandum of Understanding with WFDB and being there gave me the additional opportunity to speak with many DbI organisations, Individual members and people with deafblindness, that all attended the WFDB General Assembly and the 11th Helen Keller World Conference.



# Deafblind

International DbI

We have developed a new logo for DbI which is displayed in this edition. This has given us a new modern look with the helping hands and world globe added. Note that this new logo retains the previous colours as acknowledgement of our history.

#### Memberships

DbI Treasury and DbI Secretariat have been working with new software packages to better maintain our membership database in a secure format. This has caused some problems with the crossover of software plus we had some issues with the DbI website update. These problems have been focused on and rectified, and we are confident that the membership information is up to date.

Please check that your memberships are current and contact details are up to date. All 2018 membership invoices were sent out in February 2018 but we are still following up with people and organisations that have outstanding memberships due.

#### You can contact DbI Secretariat at:

[secretariat@deafblindinternational.org](mailto:secretariat@deafblindinternational.org) if you require your contact details to be updated or have a membership invoice resent.

#### Via the Networks on the website:

[www.deafblindinternational.org/networks.html](http://www.deafblindinternational.org/networks.html)



[www.facebook.com/dbiint](https://www.facebook.com/dbiint)

**Gary Daly, DbI Secretariat**  
Proudly Hosted by Able Australia  
[Gary.Daly@ableaustralia.org.au](mailto:Gary.Daly@ableaustralia.org.au)

## Lifetime Achievement Award

### BARBARA MASON

As an outstanding educator for 40 years, Barbara Mason has contributed to the lives of many individuals who are deafblind. She began her career as a teaching assistant in the Deafblind Program at Perkins, eventually going on to receive a degree in deafblind education from Boston College.



**B**arbara started her career working with students with Rubella Syndrome. Little was known about how to teach these children at that time in the early 1970's. She created a curriculum for these students; always recognizing these students as capable of learning. Her colleagues reported that she was able to capture the personalities of the students she worked with. Her interest and skills in transition, helped prepare the students for life after school.

In her role as Educational Director at Perkins, she provided leadership and support in the development of an educational program that was individualized with the goal of allowing each individual to lead meaningful adult lives. As well, her goal was always to promote a school environment that promoted the principle of dignity for all students.

In addition to her job responsibilities, Barbara was active at the state (Massachusetts), national and international levels. She oversaw the delivery of training and technical assistance to benefit students and their families in several New England states. She was also actively involved for a number of years with DbI as a member of the Board as well as serving on special committees.

Barbara gave 'her all' to provide the state of the art programs for deafblind individuals. She was also known as someone who led her team to continuously improve; doing this with grace, a positive attitude and a great sense of a humor.

**DbI congratulates Barbara Mason for all her contributions, influence and commitments to all people who are deafblind.**

## Lifetime Achievement Award

### PILAR GOMEZ VINAS

Pilar has filled many roles throughout her career in Spain as teacher, psychologist, speech therapist and administrator.



**DbI congratulates Pilar Gomez for all her contributions, influence and commitments to all people who are deafblind.**

**T**hroughout her career, Pilar's focus was to create a model that would address the needs of individuals who were deafblind throughout her country. She always believed that anyone with deafblindness could realize his/her full potential and have a productive life if the proper resources are provided.

She knew from the beginning that one of the key elements of a quality program for these individuals were well trained professionals. She organized training courses and seminars; partnered with government officials, communication support professionals, and volunteer groups.

Communication, cognition and language were areas that Pilar gained expertise. As part of her work she carried out assessments, developed educational programs and offered guidance to students and their families. Seeing the need for support that the individuals needed, she fostered and created the role of the Intervenor as well as developing competencies needed by the Intervenor.

Outside of ONCE, the organization she worked for, Pilar worked cooperatively to maintain partnerships with other organizations. This included improvements to the Spanish Legislation in support of deafblind people. She also played a fundamental role in the development of the only Residential Center for people with deafblindness in Spain. Pilar has published several articles related to deafblind education.

As a member of the DbI Board for 24 years, Pilar participated in the professionalization of DbI and its growth as an organization. She facilitated the Spanish translation of the DbI Review in order to share knowledge with professionals around the world.



## Distinguished Service Award

### MARIA BOVE



**M**aria Bove has spent a 40-year career dedicated to access to and inclusion in education for children who are deafblind. She has served in many roles: teacher, program director, university professor, researcher and international trainer.

Maria is well known in the field for the trainings she has provided to hundreds of people throughout Latin America. Her enthusiasm and high level of energy has motivated so many to become teachers. Her teacher-students have described Maria as “a force with passion” and her classes being life changing for them. Her level of energy would never allow a student to doze off during a class!

Maria believes that all children, no matter their disability, deserve a quality education equal to their non-disabled peers. She not only has had an impact on

persons with disabilities but also on the families of those she worked with. She provided family the knowledge and courage to be advocates for their children.

During her career Maria was the lead on several research projects, creating written material for Ministries of Education and for Universities. She was active advocating for the inclusion of students with multiple disabilities and deafblindness into regular schools.

Maria’s warm personality has helped her create collaborative networks between institutions at the national and international level. It was always hard to say no when she presented a proposal for services. Her knowledge, conviction and commitment have changed the lives of many children, young adults and their families in Latin America and the Caribbean.

As well, Maria has participated in numerous DbI conferences; contributing strongly to the field through her presentations and workshops.

**DbI is proud to present Maria Bove with the Distinguished Service Award.**



## STRATEGIC PRIORITIES JUNE 2015-AUGUST 2019



### Diversity

DbI will become a diverse organisation in all aspects including membership and Board representation.

**1** PRIORITY ONE



### Share Knowledge

DbI will support our networks to share knowledge and develop partnerships.

**3** PRIORITY THREE



## Social Media & Information Technology

DbI will invest in technology and social media to connect with our members and the global community.

**2** PRIORITY TWO



**Deafblind**  
International DbI

# Strategic Plan Update

Carolyn Monaco, Strategic Planning Officer

We are now three years into our four-year strategic plan and continue to make progress in all three of our strategic priority areas.

## PRIORITY # 1 – DIVERSITY

**Goal:** DbI will create a climate of diversity throughout all aspects of our operation.

### Progress Update

- Along with ManCom many members of the Board, our Networks and our Individual members appear to be thinking, writing, saying and doing more with a view to increased diversity of all types.
- The article by Dennis Lolli and Graciela Feroli in our last edition of *DbI Review* titled *Diversity: Deafblind International's Strategic Plan Moves Forward* and placed prominently on pages 5 to 8 is not only very informative but a great reflection of the DbI philosophy on diversity.
- Many of the tweets Graciela has sent on behalf of DbI have related to our diversity goals by highlighting field related news from places, programs and individuals that otherwise might not be heard from.
- DbI announced that the conference in 2021 will take place in Africa
- Decisions around how our sponsorship funds are distributed have used diversity as part of the criteria
- Representation on the new nominations committee is more diverse
- DbI has facilitated sponsorships of memberships in the organization by making connections between individuals and organizations looking to sponsor with those in need of sponsorship

## PRIORITY # 2 – SOCIAL MEDIA

**Goal:** DbI will ascertain the needs and invest in the technology and training required to enhance our ability to share knowledge and to use social media to connect with our members and the global community.

### Progress Update

- The hiring of Graciela Feroli has made a significant difference in DbI's social media presence
- Not only have her tweets increased the DbI social media presence but so have the retweets of many of our members and followers
- The transition from the previous website to the new one continues and while not without a few challenges we believe all aspects to be working well now

## PRIORITY # 3 – NETWORKS

**Goal:** DbI will support our Networks to develop competencies, share specialist knowledge and strengthen connections.

### Progress Update

- The DbI CHARGE Network held a full day Pre-conference at the conference in Denmark in September 2017
- A new DbI network called Adapted Physical Activity (APA) was established in the fall of 2017
- Seven of the fourteen Networks contributed to Edition 60 of the Review
- The DbI Network of the Americas hosted a conference in April 2018 along with a membership meeting
- The Youth Network hosted a three-day event in June in Switzerland



# DbI Review – Sponsorship Guidelines

Corporate Member Organizations are invited to sponsor future editions of *DbI Review*. If interested, check out the Guidelines below.



**Deafblind**  
International DbI

The purpose of Deafblind International (DbI) is to bring together professionals, researchers, families, people who are deafblind and administrators to raise awareness of deafblindness. Central to our work is to support the development of services to enable a good quality of life for children and adults who are deafblind of all ages.

One activity that assists in promoting the purpose of DbI is via the "*DbI Review*" biannual publication. This publication is coordinated and edited by the DbI Information Officer.

The opportunity should be provided to all corporate members and other organisations that support the Mission and Vision of DbI to sponsor the *DbI Review*. In order to achieve this, sponsorship information should be published in each edition of the *DbI Review* and also on the website.

## Applying for Sponsorship of an Edition of the *DbI Review*

Applicants requesting sponsorship should have similar social values as DbI and have an interest in the well-being of individuals who are deafblind.

The DbI Management Committee (ManCom) must endorse all sponsorships to the *DbI Review*. The Secretariat will inform applicants of the outcome of their request for sponsorship following a decision by ManCom.

Applications should be received by the DbI Secretariat. The Secretariat will then work with the Information Officer to ensure that the details of the sponsorship commitments by both the sponsor and DbI are followed through on.

## Sponsorship Levels, Costs and Entitlements of *DbI Review*

### Level 1 Sponsorship = 8000 Euro

There can be only one Level 1 sponsor. If a Level 1 sponsor is approved, then there will be no other levels of sponsorship permitted within that *DbI Review* edition. A Level 1 sponsor will have the following entitlements within one edition of *DbI Review*:

- Exclusive sponsorship rights of that *DbI Review*
- Name on bottom of front cover of *DbI Review*
- Supply photograph to be used on front cover of *DbI Review*
- Have input into the theme for the publication
- Full page advertisement
- 3 articles (related to individuals who are deafblind)
- 25 x extra copies of *DbI Review*

### Level 2 Sponsorship = 4000 Euro

There can be only two Level 2 sponsors. A Level 2 sponsor will have the following entitlements to one edition of *DbI Review*:

- Half page advertisement
- 2 articles (related to individuals who are deafblind)
- 15 x extra copies of *DbI Review*

### Level 3 Sponsorship = 2000 Euro

There are no limits to how many Level 3 sponsors can be approved. A Level 3 sponsor will have the following entitlements to one edition of *DbI Review*:

- Quarter page advert
- 10 x extra copies of *DbI Review*

For all levels of sponsorship, DbI reserves the right to not publish submissions that we deem for any other reason to be unsuitable, unlawful, or objectionable, such as but not limited to the content of the material (for example, the usage of inappropriate language), the subject matter, the timeliness or relevance of the material, or reasons related to intellectual property, among others.

## Successful Applicants

Successful applicants will be notified no later than one month following their application submission to the publication of the *DbI Review* they wish to sponsor.

Applicants to accept or decline the sponsorship no later than four and a half months prior to the publication of the *DbI Review*.

The agreed amount of sponsorship funds will be transferred to the nominated account no later than 3 months prior to the publication date of the *DbI Review* they will sponsor.

Funding can only be accepted in Euros and not in any other currency.





## Honorary Officers

### President

**Gillian Morbey**  
Sense UK  
Email: Gillian.Morbey@sense.org.uk

### Vice-President

**Bernadette Kappen**  
The New York Institute for  
Special Education  
Email: bkappen@nyise.org

### Vice-President & Treasurer

**Frank Kat**  
Royal Dutch Kentalis  
Email: F.Kat@outlook.com

### Immediate Past President

**William Green**  
Email: green.lfo@usa.net

### Secretary

**Gary Daly**  
Able Australia  
Email: gary.daly@ableaustralia.org.au

### Strategic Plan Officer

**Carolyn Monaco**  
Canadian Deafblind Association  
Email: carolyn.monaco@sympatico.ca

### Information Officer

**Stan Munroe**  
Canadian Deafblind Association  
Email: munroes@seaside.ns.ca

### Development Officer

**Knut Johansen**  
Signo  
Email: knut.johansen@signo.no

## Networks

### Acquired Deafblind

**Network**  
**Liz Duncan**  
Email: lizduncan64@yahoo.co.uk  
Website: http://adbn.deafblindinternational.org

### Adapted Physical Activity

**or APA Network**  
**Mads Kopperholdt & Anders Rundt**  
Emails: mads.kopperfeldt@rn.dk; anmaru@rn.dk

### CHARGE Network

**Andrea Wanka**  
Email: aw@andrea-wanka.de  
Website: http://chargenetwork.deafblindinternational.org

### Communication Network

**Marleen Janssen**  
Email: h.j.m.janssen@rug.nl  
Website: http://communication.deafblindinternational.org

### EDbN

**Ricard Lopez Manzano**  
Email: rlopez@edbn.org  
Website: http://edbn.deafblindinternational.org

### Ibero Latin American

**Network**  
**Vula Ikonmidis**  
Email: vula2004@hotmail.com  
Website: http://iberolatineramerican.deafblindinternational.org

### Network of the Americas

**Marianne Riggio**  
Email: Marianne.Riggio@Perkins.org  
Website: http://americas.deafblindinternational.org

### Outdoor Network

**Joe Gibson**  
Email: deafblindoutdoors@gmail.com  
Website: http://outdoornetwork.deafblindinternational.org

### Research Network

**Walter Wittich**  
Email: walter.wittich@umontreal.ca  
Website: http://research.deafblindinternational.org

### Rubella Network

**Nigel Turner**  
Email: nigel.turner@sense.org.uk  
Website: http://rubella.deafblindinternational.org

### Social-Haptic

**Communication Network**  
**Dr. Riitta Lahtinen & Russ Palmer**  
Email: riitta.lahtinen@icloud.com; rpalmer2@tiscali.co.uk  
Website: http://socialhaptic.deafblindinternational.org

### Tactile Communication

**Network**  
**Paul Hart**  
Email: phart@sensescotland.org.uk  
Website: http://tcn.deafblindinternational.org

### Usher Network

**Emma Boswell**  
Email: Emma.Boswell@sense.org.uk  
Website: http://usher.deafblindinternational.org

### Youth Network (DbIYN)

**Simon Allison**  
Email: simon.allison@sense.org.uk  
Website: http://dbiyn.deafblindinternational.org

## Large Corporate Members

### AUSTRALIA

**Able Australia**  
Kate MacRae  
Email: kate.macrae@ableaustralia.org.au  
Website: www.ableaustralia.org.au  
**Senses Australia**  
Matthew Wittorff  
Email: matthew.wittorff@senses.org.au  
Website: www.senses.org.au

### CANADA

**Canadian Deafblind Association Ontario Chapter**  
Cathy Proll  
Email: cproll@cdbaontario.com  
Website: www.cdbaontario.com  
**DeafBlind Ontario Services**  
Roxanna Spruyt-Rocks  
Email: ceo@deafblindontario.com  
Website: www.deafblindontario.com

### DENMARK

**Interfond**  
Pierre J. Honoré  
Email: pjh.interfond@mail.dk

### GERMANY

**CBM – Christoffel Blindenmission**  
Monika Brenes  
Email: Monika.Brenes@cbm.org  
Website: www.cbm.org

### German Deafblind Consortium

Roland Flaig  
Email: roland.flraig@stiftung-st-franziskus.de

### ITALY

**Lega del Filo d'Oro**  
Rosanno Bartoli  
Email: info@legadelfilodoro.it  
Website: www.legadelfilodoro.it

### SPAIN

**ONCE**  
Eugenio Romero Rey  
Email: err@once.es  
Website: www.once.es

### SWEDEN

**Mo gård**  
Lena Goransson  
Email: lena.goransson@nckdb.se  
Website: www.mogard.se

### THE NETHERLANDS

**Royal Dutch Kentalis**  
Maria Brons  
Email: maria.brons@kentalis.nl  
Website: www.kentalis.nl

### UNITED KINGDOM

**Sense**  
Gillian Morbey  
Email: Gillian.Morbey@sense.org.uk  
Website: www.sense.org.uk  
**Sense Scotland**  
Andy Kerr  
Email: akerr@sensescotland.org.uk  
www.sensescotland.org.uk

### USA

**Perkins International**  
Marianne Riggio  
Email: Marianne.riggio@perkins.org  
Website: www.perkins.org

## Small Corporate Members

### ARGENTINA

**Latin America and Caribbean Perkins International**  
Gloria Rodriguez-Gil  
Email: gloria.rodriguez@perkins.org

### AUSTRALIA

**Deafblind Australia**  
David Murray  
Email: info@deafblind.org.au  
Website: www.deafblind.org.au  
**Forsight Australia**  
Trish Wetton  
Email: forсайт.аus@forsight.net.au  
Website: www.forsightaustralia.org.au

### AUSTRIA

**Österreichs Hilfswerk für Taubblinde**  
Christa Heinemann  
Email: c.heinemann@zentrale.oehbt.at  
Website: www.oehbt.at

### CANADA

**CDBA National**  
Carolyn Monaco  
Email: carolyn.monaco@sympatico.ca  
Website: www.cdbanational.com  
**Canadian Helen Keller Centre**  
Jennifer Robbins  
Email: jrobbins@chks.org  
Website: chks.org

### ICELAND

**The Lions McInnes House – Group Home for Deafblind Persons**  
Laurie Marissen  
Email: LionsMcInnesHouse@rogers.com  
**Canadian National Institute for the Blind (CNIB)**  
Email: Sherry.Grabowski@cnib.ca  
Website: www.cnib.ca

### CHINA HONG KONG

**Resource Centre for the Deafblind**  
**The Hong Kong Society for the Blind**  
Doreen Mui  
Email: doreen.mui@hksb.org.hk  
Website: www.hksb.org.hk

### CROATIA

**Mali dom – Zagreb**  
Darja Udovicic Mahmuljin  
Email: darja@malidom.hr  
Website: www.malidom.hr

### CYPRUS

**Pancyprrian Organization of the Blind**  
Christakis Nikolaidis  
Email: pot@logos.cy.net

### DENMARK

**Center for Deaf Karin Moreau Andersen**  
Email: kma@cfd.dk  
Website: www.cfd.dk  
**Socialstyrelsen**  
Trine Skov Uldall  
Email: tul@socialstyrelsen.dk  
Tel: (45)+98854332  
Email: faurholt@mail.tele.dk  
**Danish Parents Association**  
Vibeke Faurholt  
Tel: (45)+98854332  
Email: faurholt@mail.tele.dk  
**The Center For Deafblindness and Hearing Loss (CDH)**  
Lars Søbye  
Email: laejs@rn.dk  
Website: www.dbcn.dk

### FINLAND

**The Finnish Deafblind Association**  
Sanna Nuutinen  
Email: sanna.nuutinen@kuurosokeat.fi  
Tel: +358 40 529 3439  
+358 40 604 7477  
Website: www.kuurosokeat.fi

### FRANCE

**RFPS-ANPSA**  
Dominique Spriet  
Email: presidence@anpsa.fr

### GREECE

**Hellenic Association of Deafblind "The Heliotrope"**  
Diamanto-Toula Matsa  
Email: diamatsa@gmail.com

### ICELAND

**National Institute for the Blind, Visually Impaired and the Deafblind**  
Estella D. Björnsdóttir  
Email: estella@midstod.is

### INDIA

**Sense International (India)**  
Akhil Paul  
Email: akhil@senseindia.org  
Website: www.senseindia.org

### IRELAND

**The Anne Sullivan Centre**  
Grace Kelly Hartnett  
Email: gracekellyh@annesullivancentre.ie  
Website: www.annesullivan.ie

### NEW ZEALAND

**Royal New Zealand Foundation for the Blind (RNZFB)**  
Jill Baldwin  
Email: jballdwin@blindfoundation.org.nz  
Website: www.rnzfb.org.nz

### NICARAGUA

**Asociacion de Sordociegos de Nicaragua**  
Mireya Cisne Caceres  
E-mail: sordociegosnicaragua@hotmail.com

### NORWAY

**Signo kompetansesenter**  
Anne Lise Høydahl  
Email: anne.lise.hoydahl@signo.no  
**Signo Vivo**  
Knut Johansen  
Email: knut.johansen@signo.no  
Website: www.signovovindesenter.no  
**Eikholt**  
Roar Meland  
Email: roar.meland@eikholt.no  
Website: www.eikholt.no

### STATPED

Bitten Haavik Ikdahl  
Email: Bitten.H.Ikdahl@statped.no

### National Advisory Unit of deafblindness

Eva Hirsti  
Email: eva.hirsti@unn.no  
**Regional Center for people with deafblindness**  
Eva Hirsti  
eva.hirsti@unn.no

### RUSSIA

**Deaf-Blind Support Fund "Con-nection"**  
Dmitry Polikanov  
Email: d.polikanov@so-edinenie.org  
Website: www.so-edinenie.org

### SINGAPORE

**Lighthouse School**  
Koh Poh Kwang  
Email: kohpohkwang@lighthouse.edu.sg  
Website: www.lighthouse.edu.sg

### SPAIN

**Federation of Associations of Deafblind People (FASOCIDE)**  
Francisco Javier Trigueros Molino  
Email: internacional@fasocide.org.es  
Website: www.fasocide.org  
**Spanish Association of Parents of Deafblind People (APASOCIDE)**  
Dolores Romero Chacon  
Email: apasocide@apasocide.org  
Website: www.apasocide.org  
**Spanish Federation of Deafblindness (FESOCIE)**  
Ricard Lopez i Manzano  
Email: fesocie@fesocie.org  
Website: www.fesocie.org

### SWEDEN

**National Resource Centre for Deafblindness**  
Lena Goransson  
Email: lena.goransson@nckdb.se  
Website: www.nckdb.se  
**Nordic Welfare Centre**  
Maria Creutz  
Email: nvcdb@nordicwelfare.org  
Website: www.nordicwelfare.org

### Specialpedagogisla

**Skolmyndigheten**  
Mia Martini  
Email: mia.martini@spsm.se  
Website: http://www.spsm.se

### SWITZERLAND

**SZB Beratungsstellen für hörschbehinderte und taubblinde Menschen**  
Mäde Müller  
Email: mueller@szb.ch  
Website: www.szb.ch  
**Tanne, Schweizerische Stiftung für Taubblinde**  
Mirko Baur  
Email: mirko.baur@tanne.ch  
Website: www.tanne.ch

### THE NETHERLANDS

**Bartimeus**  
Betty van Wouw  
Email: bwwouw@bartimeus.nl  
Website: www.bartimeus.nl  
**Kalorama, Centrum voor doofblinden**  
Els Peters  
Email: e.peters@kalorama.nl  
Website: www.kalorama.nl

### Koninklyke Visio

Marie-José van den Driessche  
Email: MarieJosevandenDriessche@visio.org  
Website: www.visio.org

### University of Groningen

Marleen Janssen  
Email: h.j.m.janssen@rug.nl

### UNITED KINGDOM

**Sense International**  
Alison Marshall  
alison.marshall@senseinternational.org.uk  
Website: www.senseinternational.org

### Scene Enterprises CIC

David Sutton  
Email: david.sutton@sceneenterprises.org.uk  
Website: www.sceneenterprises.org.uk

### UNITED STATES OF AMERICA

**The New York Institute for Special Education**  
Bernadette Kappen  
Email: bkappen@nyise.org  
Website: www.nyise.org  
**Overbrook School for the Blind**  
Jackie Brennan  
Email: jackie@obs.org  
Website: www.obs.org  
**Texas School for the Blind & Visually Impaired – Texas Deafblind Project**  
Cyril Miller  
Email: cyrilmiller@tsbvi.edu  
Website: www.tsbvi.edu/deaf-blind-project

## Mini Corporate Members

### ETHIOPIA

**Ethiopian National Association of the Deafblind (ENADB)**  
Roman Mesfin  
Email: enadb@ethionet.et

### MALAWI

**Visual Hearing Impairment Membership Association (VIHEMA Deafblind Malawi)**  
Ezekiel Kurnwenda  
E-Mail: vihemadefblindmalawi@gmail.com

### African Federation of Deafblind (AFDB)

Ezekiel Kurnwenda  
Email: afdb.secretariat@gmail.com