

## **DbI Review**

Number 53 • July 2014

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

DbI Review is published twice yearly, the two editions are dated January and July. The editor will be pleased to receive articles, news items, letters, notices of books and information on forthcoming events, such as conferences and courses, concerning deafblind children, young adults and older people. Photographs are welcome.

All written material should be in the English language and may be edited before publication. It should be sent for publication to arrive by the date below.

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:

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Cover: Multi-Partner Total Communication at Rafaël School

LAST COPY DATE FOR THE NEXT EDITION: 17 OCTOBER, 2014

## **A message from the president**

**Dear Friends and colleagues,**

Our last Management Committee (Man Com) meeting was held in Bucharest, Romania on the 8th and 9th March 2014. We were of course preparing for our Dbl World conference in May 2015. We were hosted by the local planning committee led by Cristiana Salomie and met with the scientific committee led by Tony Best. We met at the conference venue and were able to see first-hand the arrangements and facilities for next year.

As always Dbl conferences try to 'spotlight' the work undertaken in a particular country and, if we have any influence, give some impetus to move discussions and services forward. We are hopeful that this conference will do the same but also have an impact on wider developments throughout Eastern Europe. Services are still incredibly patchy with some countries having no post school provision. I know this is of great concern to the families who are undertaking a huge amount of work to develop services for their children as they grow older.

We reviewed the reports of the networks and are delighted with the continuing and developing work. Fundraising and our strategic plan are always on the agenda along with our budgets and finance. Our information services continue to develop and more and more attention is being given to our website and social media.

I was particularly honoured to be in Barcelona in June for the conference and launch of the 'Mapping Opportunities for Deafblind People across Europe' report. The project was developed by members of the European Deafblind Network (EDBN) and funded by the European Commission. The report is a major achievement with 27 European states/regions responding to the request for information and nine core organisations working together for two years.

At the time of producing this edition the report has just been published so I am sure members will receive more detail in due course. In the meantime I would like to congratulate all those involved.

The Man Com looks forward to welcoming the Board members to Belfast in November 2014. The ADbN Conference comes at an important time for recognition of Deafblindness as a unique disability in Northern Ireland so I know it will be well supported.

Kindest regards to all  
Gillian Morbey President Dbl

## Editorial

Dear friends,

I am pleased to say that this edition is 'bursting at the seams' with material, indicating the growth of programs geared to improving the lives of people with deafblindness around the world.

As someone involved in this field for over 40 years, it is so remarkable to observe the developments that are taking place internationally. It's such a privilege as the magazine editor, to ensure that the authors of these articles have a platform to tell their stories and share with their colleagues the work they are engaged in.

The deafblind community worldwide has benefited from the services of international foundations such as Sense International, Perkins International, Kentalis and Christian Blind Mission International (CBM). There are a number of great articles in this edition that demonstrate their support and commitment to build local capacity and services in Latin America, Africa, Eastern Europe and Southeast Asia.

This edition also highlights some of the continuing important service and research work undertaken by organizations in Australia, Canada, India and Europe featured in the 'Country News' section and elsewhere in the magazine.

As with the last edition, we are again featuring a CHARGE related paper from Dr. Tim Hartshorne (and his colleagues), titled "Self-Regulation of Cognition in CHARGE Syndrome". Watch for additional related articles from Dr. Hartshorne and colleagues in future editions. To complement these articles, Dr. Susan Bruce from Boston University and Physical Therapists Danielle Bushey and Mary Poblete from Perkins School for the Blind present a paper demonstrating how physical therapy can help children with the physical and sensory challenges resulting from CHARGE Syndrome gain confidence to participate in life activities.

A Dbl Conference in Canada (2003) had as its' theme: 'Communication is the Key to opening doors for people with deafblindness'. Two articles from Kentalis in the Netherlands, (one academic and one practical) substantiate the validity of this statement. The academic article from Marga Martens and Marleen Janssen 'Developing evidence-based methods for improving high quality interpersonal communication with people who are congenitally deafblind' suggests that mutual contact between congenitally deafblind persons and their communication partners (intervenors) help reduce stressful experiences and ensures enjoyment in relationships. The practical article from Kentalis Rafaël School is an exciting approach to tactile communication involving multi-partners in contrast to the typical one-on-one interaction between a deafblind person and their communication partner or intervenor. According to the authors, their students enjoy their multi-partner tactile interactions; appearing to be more conscious of their surroundings and the people around them involved in this communication process.

Susannah Barnett's has a provocative research article titled 'Congenital Rubella Syndrome-An Emerging Multi-Faceted Relationship'. Susannah, who has CRS, approaches her research not strictly from a health impacts basis but from the

perspective of what she calls the 'multi-faceted social relationship' impacts that result from this disability on the person with CRS, their family and caregivers. The article from Lega del filo d'oro (Italy): 'Theatre: a big adventure on the road to rehabilitation' marks the third deafblindness related theatre group featured in recent editions. In edition 52 (January 2014), the theatre group Toneel Mooi Uitzicht from Stichting Kalorama (Netherlands) was featured; and the January 2012 (edition 48) highlighted the Nalaga'at theatre group from Israel. Coincidentally, the article from Senses Foundation in Australia features a recent visit from the Nalaga'at theatre troupe to Perth.

Lastly, Dbl Review congratulates Kentalis for its generous sponsorship of this the 53rd edition of the magazine. A full page advertisement from Kentalis is featured in the inside of the last page. We hope others may offer some degree of sponsorship support for future editions. Check out the article on Dbl sponsorship guidelines found near the end of the magazine.

Happy Reading

**Stan Munroe**

## **Vice Presidents' Messages**

**Bernadette Kappen:**

Deafblind International is strong because of the participation of the members of the board and the organizations represented as well as the individual members of Dbl. Our goal is to increase membership and encourage professionals, parents and consumers working in the field of deafblindness to join "their organization". Being involved with Dbl puts you in contact with others and gives you the opportunity to learn about programs throughout the world. As we prepare for the world conference in Bucharest in 2015, it is a time for each of us to encourage individuals we know to join Dbl. The conference will increase our knowledge and skills and put us in contact with others working in the field.

Everyday around the world, individuals working with individuals who are deafblind make outstanding contributions. I think it is fair to say that the people who work with individuals who are deafblind are highly motivated, creative and positive individuals. These are the people we want to honor in Bucharest in 2015. It is time to think about nominating individuals for the Distinguished Service and the Lifetime Achievement Awards. These awards have typically been given to individuals who have had a long career in the field of deafblindness. In reviewing the awards given, it became clear that we have many emerging leaders in the field. To recognize their achievements we have developed the Young Professional Leadership Award. The criteria for the awards will be on the Dbl website. Nominations are due by January 23, 2015 and should be emailed to Bernadette Kappen at [bkappen@nyise.org](mailto:bkappen@nyise.org).

I hope you will review the criteria and think of individuals you work with who deserve recognition for their work. It is the individuals working in the field who improve the lives of individuals who are deafblind and strengthen the work of Deafblind International.

**Bernadette Kappen**

**Carolyn Monaco:**

With the publication of each issue of our “Review” magazine, reflecting on the progress of DbI and the organizations for which I work and volunteer here in Canada always seems to be part of the process for me. What always stands out during my reflections are the people, and the long-standing relationships so many of them have had with this field. That’s the good news.

More recently, with the retirements and unfortunate passing of some of our colleagues I am reminded of the responsibility we all have to ensure the long-term future of our field, our organizations and the services required by individuals who are deafblind, their families and their communities.

It seems sometimes that in our day-to-day work we have become so busy with the present that taking the time to ensure that there will be a generation of future colleagues prepared for the challenges they may face is difficult. That’s the bad news.

People who had a passion for this field, who worked hard, who were determined, who collaborated, who shared generously... and yes who had a little luck, have gotten us where we are today. We have a strong history and we need to ensure an even stronger future.

Did you mentor someone today?

**Carolyn**

## **DbI World Conference**

**Tony Best, Chair of the Scientific Committee, in conversation with James Thornberry, member of the Conference Management Group**

1. Why did the Scientific Committee choose the conference theme: Local solutions to common needs; what is the future?

Members of the Scientific Committee come from eight different countries<sup>1</sup>. At our first meeting, we talked about what was happening in the field of deafblindness in our own countries. We were struck by the very different approaches that we each

considered as common, and excellent. We realised that our field had now developed to a stage when it was possible for services, regions and countries to feel confident enough to work in ways they felt comfortable; that fitted in with their culture and values. No longer was there just one 'right' approach to working with people who are deafblind. Now we had many approaches to meeting those needs that often come with deafblindness.

This exciting discovery seemed to be a good theme for a conference in 2015. We hope to celebrate the many different ways in which people with deafblindness are being supported; this is why we have the theme 'local solutions to common needs'. We added the question 'what is our future?' to test if this is really how the field will develop. Is it true that regions will continue to each develop their own approaches? Or, given that deafblindness creates similar issues wherever it occurs, will common approaches emerge as the 'best' way to work? Are we in one global village connected by easy e-communications, or will we recognise the importance of our local culture and further develop our own identities?

2. Have you planned the programme with anything new or different?

Yes, we think of this as a participants' conference.

There will be 3 plenary sessions that we anticipate being discussions rather than just as series of presentations. We will announce these when the details are finalised, later in the year. For the latest information go to the website

[www.dbi2015romania.com](http://www.dbi2015romania.com)

But most of the time will be taken up with workshops and poster sessions. Both will be equally important, and provide an opportunity for a presenter to talk with a group of interested participants about their topic. The workshops will be active learning experiences and, like the poster sessions, with the opportunity to have a discussion with the presenter (although this is not essential - you can just observe and enjoy the sessions).

We expect there to be a large demand for the limited number of workshops and poster sessions so, if you want to share your ideas and experiences, I urge people to apply for a session as soon as possible, and certainly by the end of September at the latest.

You will notice that I used the word 'participants' and that is what we are calling people who attend the conference, rather than attendees or delegates. This is planned as a conference which involves participants throughout the days.

3. I heard that there will not be the usual day for cultural visits. Is this true?

We carefully considered whether to include a tourism day during the week. We recognised that people who do not speak English as their first language might need time away from the conference for a rest. We know that people who use sign languages can become tired more quickly than people who listen to presentations. After careful consideration, and hearing about the experience of previous conferences, we decided to put the city visits and day tours in Romania at the end of the conference. The organizers will offer a fabulous chance to visit the beautiful areas outside Bucharest or to take a half day tour of the city.

There will be rest times within the days; for example up to 2 hours for lunch. Participants can decide for themselves whether to attend one of the many parallel sessions, have a rest, or arrange a small group meeting. Any optional evening sessions will take place after the end of the formal sessions to allow for a rest time. Again, the emphasis is on participants being able to choose how to use their time and to decide how they will spend their days at the conference.

A word of advice: the conference hotel, the JW Marriot, will be the most convenient hotel for people who want to join in most of the optional evening sessions. The other hotels involve a walk or taxi ride.

4. What do you hope will be the legacy of this conference?

We hope that many of the sessions will be recorded in some form so they can be reviewed by participants after the conference. There may be written record of proceedings, but this is more likely to be in some electronic form.

In terms of knowledge, though, we hope this conference will give a record of the many excellent ways that the needs of people with deafblindness can be met. This will provide a rich resource for colleagues, and particularly for the very many isolated programmes that are developing pioneering work throughout the world.

We plan for the final conference session to be a series of 'thought pieces' - ideas from participants about their futures, and what information from the conference might inspire their future work. There will be no right or wrong answers; each participant can decide. And the question 'what is our future?'; again participants will decide. Please do come to the conference, join in, and be part of this exciting discussion about our future.

Thank you

Tony Best  
Chair Dbl Conference Scientific Committee  
Email: [tonybest987@gmail.com](mailto:tonybest987@gmail.com)

**As a person with Deafblindness, what have the organisers done to ensure that the barriers to participation for the 2015 Dbl Conference in Bucharest have been understood and my rights accommodated?**

**Anya Rakoczi, a member of the Conference Management Group answers this question.**

Preparations for Bucharest 2015 are underway and the conference is set to deliver a programme to inspire ideas, stimulate debate and encourage practice sharing. A further, less celebrated but equally important, aspect of the conference is that it is being designed to be accessible for all. In Bucharest 2015 having a dual sensory loss will not mean your experience is any less fulfilling and productive.

Proudly advocating an individual approach to an international conference we will work with participants to do what we can to ensure the conference runs smoothly for everyone.

The array of communication support which will be happening and in a variety of languages is a logistical feat. Whether highly visible on the platform or behind the scenes, delegate's access to information, ability to communicate and get around the JW Marriott Hotel and Bucharest is being considered at every stage. From platform International and Romanian interpretation in plenary sessions, to a venue familiarisation tour, to downloadable documents online – we are committed to reduce barriers to information and participation that those with a dual sensory loss can otherwise face. You may be pleased to see breakfast menus produced in Braille; perhaps the English captioning in plenary sessions will make following a speaker easier, or the reduced background music in the restaurants means conversation will flow better. From small touches to larger commitments accessibility considerations will run through the heart of the conference.

A further promise to participants is that we will be honest when we cannot do something. It would be financially impossible to assume all support needs for all. For this reason a Statement of Accessibility can be found on the conference website which states what provisions will and will not be at the conference, enabling participants to take responsibility and control of their communication needs.

Our approach is steadfast – we will provide what we can to support communication for all but be open about what will not be possible, and, we will listen, understand and work with participants to find individual solutions to meet their needs.

Anya Rakoczi

Email: [Anya.Rakoczi@sense.org.uk](mailto:Anya.Rakoczi@sense.org.uk)

16th Dbl Conference on Deafblindness

DRAFT PROGRAMME\*

Monday, May 25

19.00 Welcome Cocktail

JW Marriott Grand Hotel – Lobby

Tuesday, May 26

10:00 – 11.00 Official opening of the conference

11.00 – 11.30 Coffee Break

11.30 – 12.30

Plenary Session:

Introduction to the conference;

Local Solutions to Common Needs

12:30 – 14.00 Lunch Break

14.00 – 15.45 Workshops – parallel sessions\*\*

15.45 – 16.15 Coffee Break

16.15 – 18.00 Workshops – parallel sessions\*\*

Wednesday, May 27

09.00 – 09.15

Announcements / Communication Checks

09.15 – 12.30

Plenary Session: Learning and education – Part 1

An eminent speaker will discuss the human need for learning and how this might be disrupted by deafblindness

10.30 – 11.00 Coffee Break

11.00 – 12.30

Plenary Session: Learning and education – Part 2

Three respondents describing how the need for learning has been met in local services

12.30 – 14.00 Lunch Break

14.00 – 15.45 Workshops – parallel sessions\*

15.45 – 16.15 Coffee Break

16.15 – 17.00 Workshops – parallel sessions\*

10:30 – 16:15 Poster sessions

Evening: meeting zones (including 'pop-up' sessions)

Thursday, May 28

09.00 – 09.15

Announcements /

Communication Checks

09.15 – 12.30

Plenary Session:

Identity and belonging – Part 1

The introductory speaker will reflect on the need of all humans to understand their identity and to feel that they belong to a community.

10.30 – 11.00 Coffee Break

11.00 – 11.45

Plenary Session: Identity and belonging – Part 2

Three respondents, with experience of deafblindness, will describe how this has been achieved and will question and challenge.

11.45 – 12.30 Dbl Awards Ceremony

12:30 – 14:00 Lunch Break

14.00 – 14.45 Workshops – parallel sessions\*

15.00 – 15.45 Network activities – Part 1

An opportunity for Dbl networks to organise an activity, and an opportunity for all conference delegates to attend one of the Dbl network meetings, and register for future Network activities.

15.45- 16.15 Coffee Break

16.15- 17.30 Network activities – Part 2

19.30 Gala Dinner (location to be confirmed)

10:30 – 16:30 Poster sessions

Friday, May 29

09.00 – 09.15 Announcements/  
Communication Checks

09:15 – 12:15

Plenary Session:

Advocacy and Recognition

A speaker and respondent will discuss different ways that political advocacy, at personal, local and national levels, has resulted in the recognition of deafblindness – an essential starting point for the development of support services.

10.30 – 11.00 Coffee Break

11.00 – 12.15

Plenary Session: “What is our future?” Round table discussion including reflections on the impact of the conference on participants future activity

12:15- 12:45 Closing Session

13.00 – 14.30 Lunch (optional)

Upon request for the delegates who stay for the Touristic Program.

14.30 Bucharest Sightseeing Tours

Saturday, May 30 – Touristic Day

\*

Important: this programme is likely to change as speakers and their topics are confirmed

\*\*

Themes for the workshops / parallel sessions will be announced in June 2014, with an invitation to submit applications to lead a workshop session.

## **Wander, explore and discover Bucharest, Romania**

**(when you come to the 16th Dbl Conference on Deafblindness)**

**Bucharest is definitely an exciting place to visit. Not yet touched by mass-tourism, the sixth largest city in Europe is a city to explore and discover. Bucharest will host the 16th Dbl World Conference on Deafblindness, in May 25 – 30 2015.**

### **If you want a taste of good music...**

Go to the Romanian Athenaeum! An impressive edifice built over 120 years ago, the Romanian Athenaeum is not only a place for music, home to many great musical personalities and talents of the world, but also an architectural and spiritual landmark of a whole nation. Not many people know that the Athenaeum was entirely built out of public money collected through the National Lottery (500.000 tickets were issued, costing 1 Leu each).

### **If you want to experience art at its finest...**

Visit The National Museum of Art, which hosts three art galleries: The European Art Gallery, the Romanian Medieval Art Gallery and the Romanian Modern Art Gallery, bringing together art works exhibited in an attractive, modern manner, thus turning a visit to the museum into an enjoyable and instructive way of spending time.

### **If you want to explore something really special...**

Visit the Village Museum – an open-air, ethnographic museum in the heart of Bucharest, on the shores of Herastrau Lake! You will have the chance to see a real “village”, with peasant houses from all over the country and artefacts from the 17th to early 20th century, extended to over 100,000 m<sup>2</sup>. In other words, visit the Village Museum and you will get a glimpse of Romania!

### **If you want to enjoy a nice cup of coffee or a cold beer...**

You must stroll around the Old City! A combination of historical landmarks, local culture and life style, it is full of antique shops, bookstores, theatres, and dozens of cafes, bars and clubs. On warm summer nights, the place is full of colour and life, the Old City being the favourite place for locals, as well as visitors, to hang out.

### **If you want to take a nice walk...**

Go to Cismigiu Gardens! A multitude of trees, flowers, swans and lakes, Cismigiu was first designed and laid out in 1845 by the German landscape architect Carl Meyer. The park has a couple of cafes, refreshment kiosks and – in summer – terraces, as well as some good, large children's playgrounds. It can get very busy in good weather, but it is a lovely place to spend time.

### **If you want to travel back in time...**

Take a walk in Ioanid Park! An archaeological marvel of Bucharest, the area is full of sumptuous villas built during the Eclectic period, transformed into embassies and official diplomatic residences. The belle epoque atmosphere of the neighborhood will most definitely charm you.

### **If you want to be amazed...**

Take a tour of the Palace of Parliament! It is the second largest administrative building in the world, after the Pentagon. Few people know that, besides the 12 levels visible to people above ground, it has another 8 levels underground. For most locals, the massive Parliament is a physical reminder of Nicolae Ceausescu's ego and power lust, but it is a landmark worth visiting.

The list of things to see and places to visit in Bucharest can go on forever... The best way to feel a city though, is to come and see it for yourself; wander the streets, discover and explore. You will not be sorry!

Looking forward to seeing you in Bucharest, in 2015!

Check out the Dbl Conference website ([www.dbi2015romania.com](http://www.dbi2015romania.com)) to find out about these touristic opportunities.

Cristiana Salomie

Director

Sense International (Romania)

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# **Multi-partner tactile interaction**

**and communication at Kentalis school Rafaël**

**A story from the practical field by Damie van Vianen and Amanda Buijs**

**Sometimes you are so excited about a certain topic that you want to start with it straight away.**

## **Inspiration**

In August 2013, the entire team of professionals of Kentalis Rafaël attended the 8th Dbl European Conference in Lille, France. Among the inspirational workshops was: 'Participation in the narrative three-party interactional practices in the tactile modality', presented by Eija K.Lundqvist<sup>3</sup> from Norway. What appealed to us was the addition of an extra communication partner in the tactile modality and the added value this provides for people with (congenital) deafblindness.

The natural process of listening in, whether consciously or unconsciously, while others are having a conversation, provides the opportunity to experience how others communicate and offers a broader language input than one-on-one dialogues.

Listening in is not obvious for people with (congenital) deafblindness; tactile communication with several partners can provide this opportunity for them.

In recent years, tactile interaction and communication has played an increasingly important role in our school. Tactile interaction and communication with several partners is a wonderful and natural expansion of this development; a logical step that provides an additional dimension.

In order to maintain the momentum from Lille, we started planning how we could apply this in practice soon after we returned.

## **Pilot**

We decided on a pilot with three pupils from our school population. One of them, Tieme, was monitored more intensely during five sessions with an increasing length of time from 3 to 15 minutes. Tieme is a 12-year old boy with congenital deafblindness as a result of the Infantile Refsum Syndrome, which is typified by hearing loss and visual impairments. The didactic and communicative approach of recent years clearly indicates that, also as a result of coordination problems, Tieme has greatly benefited from speech supported by tactile signs. Tieme communicates mainly through (tactile) signs; the totality of his expressions consists of one to three signs.

## **Hypotheses**

We wanted to know the effects that tactile communication with various partners would have on Tieme. We expected him to become more aware of conversations others around him are having; hopeful that he would show a different type of

involvement in conversations held by communication partners, initially as a listener, then participating in an active role which would ultimately result in him adding a new initiative to the conversation.

The actual result was not all that straightforward. Tactile signing with three people took some getting used to; the realisation of proper teamwork with six hands resulted in comic situations. It went to show once more that practice makes perfect and after a couple of sessions, a reasonably smooth progress developed in the conversation and the change of hand positions.

The most essential point of departure was that it initially involves the process of the contact, the sharing of the experience or information and the development of a more solid social connection as a result of this. The contents of the conversation and the technical execution were matters of secondary importance.

## **Results**

After 2.5 months, it became clear that Tieme was indeed becoming involved in conversations between familiar people around him in another way, while he decides his role in matters. He listens, repeats, moves with others, sometimes actively engaging in events, following the emotions of his discussion partners. Tieme clearly enjoys this!

We were surprised to see that he generalises the execution of tactile discussions with various partners to other situations with other people, and observe that he involves professionals as well as pupils in the discussions!

## **Learning language**

We have new expectations for Tieme regarding learning language using this type of tactile communication. We hope that he can be taught to answer yes/no and who-what-where questions by the proper examples two competent communication partners can give. The topic of the conversations is now more important.

Another pupil from the pilot, Mick, is a 10-year old boy with congenital deafblindness as a result of premature birth. He controls a small number of signs actively considering his locomotor and sensory disabilities. We are unable to communicate with him at a linguistic level, as we could with Tieme. Consequently, we decided to consciously initiate interaction in a tactile manner with 3 or 4 partners instead of one-on-one interaction as we had previously done. This pupil also greatly enjoys the tactile interaction with several people. In addition, it makes him more conscious of his surroundings and the people in it who are in contact with him as well as with one another.

In order to share our enthusiasm and experiences with our colleagues, we decided to set up a 'knowledge café' in our school: a relaxed gathering where interesting topics are discussed. Our belief that tactile interaction and communication with various partners has added value for almost all of our pupils was confirmed by the team members who were very positive about the presentation.

The next step will be to further implement, elaborate and theoretically support this method of working more broadly.

We hope that we have been able to transfer some of our enthusiasm to the readers of this magazine. We would be happy to exchange experiences with others about this topic.

Damie van Vianen, teacher at Kentalis Rafaël  
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Amanda Buijs, speech therapist at Kentalis Rafaël  
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## **Self-Regulation of Cognition in CHARGE Syndrome**

**Benjamin Kennert, Timothy S. Hartshorne, Andrea Wanka,  
Heather Dix, Jude Nicholas**

The self-regulation of cognition is the voluntary regulation of thoughts and mental processes to balance between inhibition and initiation of behavior in order to achieve a goal. Mental processes involved may include attention, memory, learning (as well as using prior learning), reasoning, problem-solving, decision-making, metacognition, and motivation around goal directedness. A lack of cognitive self-regulation can result in the individual being unfocused. Too much cognitive regulation can result in obsession.

Cognitive self-regulation allows one to compare alternative choices, stay motivated when thinking about a problem, focus on precision and accuracy, and adapt prior learning to the current problem. It involves planning, modifying, and monitoring thoughts as they occur. In order to plan one must create a mental set of steps and remember the list while performing each step (Luna, Padmanabhan & O'Hearn, 2010). Planning requires that a goal has been set. Planning can be described as: "The process of formulating an abstract sequence of operations intended for achieving some goal" (Scholnick & Friedmann, 1987). The representation of this sequence is called a plan. A plan can both have an external and an internal representation.

Modifying thoughts is important in order to devote one's attention to the task at hand (Magar, Philips & Hosie, 2008; Turner & Hussman, 2008; Luna, et al., 2010). A person cannot effectively regulate cognitively without appropriate attention and focus on the goal. Monitoring is also important. It requires feedback, and involves thinking about thinking in order to stay on track.

Another important process involved in cognitive self-regulation is working memory. Working memory is responsible for the allocation of attentional resources during problem-solving monitoring. It is also responsible for cognitive processing that is

involved in a range of regulatory functions including the retrieval of information from long-term memory. Working memory keeps us updated on what's happening, and keeps us focused on what matters. Reduced ability to monitor the problem-solving process may result in procedural errors and incorrect associations being formed in long-term memory.

Cognitive self-regulation is difficult to study, as it can only be measured indirectly, but it is important to study. Without cognitive regulation it would be difficult to accomplish even simple tasks such as brushing one's teeth, which involves setting a goal, planning, and focusing attention. Cognitive self-regulation helps children to persist in challenging activities, which increases their opportunities to practice skills required for an activity (Florez, 2011).

Each of the three other domains of self-regulation (physiological, emotional, and behavioral) is related to cognitive regulation. Without the regulation of thoughts and mental processes people would make nonsensical behavioral choices and would have difficulty understanding and controlling emotions. Jahromi & Stifter (2008) found that a child's competence in each domain of self-regulation was related to performance in other domains. Children with greater cognitive regulation had greater behavioral control and fewer negative and aggressive behaviors related to emotional regulation (Jahromi & Stifter, 2008). Such findings show promise that, by improving cognitive self-regulation, other domains of self-regulation may also improve.

### **Self-regulation of cognition in CHARGE**

Children with CHARGE Syndrome seem to know what they want and persist in their intentions (Hartshorne, 2011). This persistence creates difficulties for parents, for when these children have an idea of what they want, they can have a lot of difficulty letting go of that idea (Hartshorne, 2011). Another challenge is that children with CHARGE often need extended time to process information (Brown, 2005). The impairments associated with CHARGE also may limit a child's awareness of internal and external stimuli, thus limiting regulatory feedback.

Ford, McDougall, and Evans (2009) suggest that an absence of incidental memory may lead to an absence of cognitive self-regulatory skills. The mind works in a systematic way to organize experiences by relating the outcomes of experiences and situations that have previously occurred. If there are problems with executive functioning of the brain, these organizational processes may not occur. Hartshorne, Nicholas, Grialou & Russ (2007), using a sample of 98 children, investigated executive dysfunction among individuals with CHARGE Syndrome using the Behavior Rating Inventory of Executive Function (Gioia, Isquith, Guy & Kenworthy, 2000). The study confirmed the presence of executive dysfunction in over half of children with CHARGE. These children displayed difficulty with items measuring shifting from one activity or focus to another, tracking their own behavior and its effect on others, and controlling their impulses and terminating behaviors as required (Hartshorne et al., 2007). Children with CHARGE have difficulty organizing thoughts. This limits the ability to use the knowledge they should have obtained from past experiences. Children with CHARGE may overlook the potential negative

consequences of their actions, and may have difficulty weighing the costs and benefits of actions (Magar, et al., 2008). If children cannot organize thoughts in a meaningful way, they may also struggle to remember strategies that have previously helped under a similar circumstance (Jahromi & Stifter, 2008).

### **Possible Interventions**

Research is needed to determine successful interventions for improving cognitive self-regulation among individuals with CHARGE syndrome. The following portion of this article will describe ideas for intervention in this area.

Using scaffolding procedures to teach a new task or to achieve a goal may be useful among individuals with CHARGE. According to Florez (2011) the most powerful way teachers can help children learn self-regulation is by modeling and scaffolding it during ordinary activities. Scaffolding involves helping the child to break down larger goals, tasks, or problems into shorter, more discrete tasks, and then teaching and modeling the task step-by-step. Starting with small tasks and concentrating on one thing allows the child to experience success, which may increase motivation. Having a system that lets the child know what they have done, and what the next step would be, and then getting the child to recognize when they are ready for the next step can be motivating and less demanding for the child. It would be important to recognize when a child is struggling to remain well-regulated and needs a more familiar, less demanding task to maintain control.

Brown (2005) suggests that trying to reduce stress levels, and trying to give the children acceptable strategies for doing so themselves, is one of the most precious gifts we can offer them. Anything that makes learning easier and reduces stress may be helpful. An example may be balancing between new and familiar activities, used flexibly. New activities may be more demanding and increase stress levels, while familiar activities may do the opposite. Modifying distracting surroundings such as noise, light, and people may also be useful for cognitive self-regulation. Providing breaks, letting the individual know that others need breaks, and making use of concrete aids are also examples of possible interventions to reduce stress.

Diamond & Lee (2011) suggest several interventions that may help develop executive functions, which could improve cognitive self-regulation. Some of these interventions include using a computer-based program to improve attention and working memory, aerobic exercises or mindfulness activities such as Tai Chi, Tae Kwon Do or yoga, and teaching different thinking strategies.

There are also several specific interventions or strategies for overcoming the limitations of the working memory. Many of these strategies have been derived from the current understanding of those cognitive processes involved in the information-processing system. These strategies or techniques can be used to minimize working memory failures and enhance the learning opportunities in individuals with CHARGE. Some of these are rehearsal or working memory load reducing strategies. Creating situations in which the child is able to concentrate on the cognitive task, without using their energy for other, different tasks, could improve cognitive self-regulation. It could be useful to prepare the child for what is going to come by having

them think about the task ahead and the goal. Allowing movement before, during, and after concentration phases may lower stress and increase motivation. Jarvela, Jarvenoja & Malmberg (2012) found that motivation is linked closely with active self-regulation among elementary school students. If possible, creating a motivating situation for the child could help greatly. A lack of motivation means that there is no emotional connection with success and then no drive for it (Turner & Hussman, 2008).

“Today I intend to polish this article! But so far it has been hard to keep my mind focused. When a new email pops up on my computer I am distracted, and if I answer it, I may even forget what I had been doing. I think about an appointment I have later in the day and my eyes leave the manuscript. I read a passage, and then wonder if that is really what we meant to say, and then my mind is no longer on the writing. To counter these forays away from the task, I re-focus my attention, re-energize my motivation, and keep telling myself to stay working and avoid the distractions”.

(Tim Hartshorne)

### **Case Example**

Matthew, almost six, who has CHARGE syndrome, is regarded as highly intellectually impaired, and is thought to be unable to refer to past experiences or separate himself from concrete objects or activities to consider something else, especially at school. One day, when lying on the floor with his mother, she asked him to drink from a blue bowl. He refused at first, then gestured to look at the bowl and carefully examined it as though it was somehow familiar and interesting. Suddenly, Matthew seemed to have a goal in mind. He asked for help standing up, and once erect looked carefully at the bowl. He was now motivated about something, and motivation is a key component of cognitive self-regulation because it involves thinking about what one wants to do and how one is going to do it. As he stood up, it was clear that Matthew needed confirmation of something with the bowl. He touched the water, and after putting it in his mouth began to make a clicking sound with his tongue to help him experience the water in his mouth. He seemed to be recalling a past event and what the experience felt and looked like. Matthew then looked in a certain direction and pointed to something, knowing his mother would follow his look. He tried to show his mother the direction to go in, which turned out to be toward a large blue, plastic pail. His experience with the small bowl of water seems to have helped him to formulate a thought of wanting to go to the pail. Several days earlier he and his brother had splashed together in the pail. Now Matthew makes a sitting motion, showing that he wants to be in the pail again. From the situation described, it is clear that Matthew has to work hard with all aspects of self-regulation. However, it is also clear that he has a strong ability to set

a goal, sustain his attention on that goal, and show others how to help him achieve that goal. It is also clear that he is able to use his working memory to mentally represent his surroundings. Matthew uses his experience, vision, and touch to help him plan and to help his mother understand what he is thinking. Seeing the small bowl with water reminded him of the large pail and he became highly motivated toward a goal. Now he needed to regulate his memory to keep focused, and maintain his attention on the goal. Because this has not been viewed as something he is skilled at or does very often, it undoubtedly took a great deal of effort and focus on his part. From this case, we can see the importance of cognitive self-regulation, as it is necessary for problem solving in each individual's own unique way. Matthew was able to:

- Use his working memory to maintain a focus on his goal
- Initiate action based on his goal
- Inhibit distracting thoughts or stimulation to get to the goal
- Problem solve how to best communicate his wants
- Engage in planning around his goal

Interventions can be planned around building on these skills; helping Matthew to make them more sophisticated. In particular scaffolding procedures might be adopted by choosing simple goals related to Matthew's interests and what he enjoys, and helping him to think about these activities, perhaps through pictures, story books, role play and modeling, and then helping him to problem solve methods for requesting access to these activities.

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## **CHARGE Syndrome and Physical Therapy**

**Danielle M Bushey, Mary Poblete and Susan Bruce**

A successful physical therapist creates a relationship of mutual trust. This respect is essential when working with children and young adults with CHARGE syndrome. The goal of physical therapy is to help these children gain confidence so they can participate in life activities through adaptation and compensation for their physical and sensory challenges. David Brown (2003) states, "Children with CHARGE are also likely to be amongst the most truly 'multi sensory impaired' people you meet, having difficulties not just with vision and hearing but also with the senses that perceive balance, touch, temperature, pain, pressure, and smell" (p. 1). Sensory and motor challenges are the result of abnormal physical structures, impaired sensory pathways, and underdeveloped processing centers. These impairments lead to deficits in balance and development of motor skills, and therefore negatively impact participation in social, academic, and vocational activities.

### **Balance**

The visual system is the primary component for balance and movement (Haibach & Lieberman, 2013). It alerts us to our environment for anticipation and adaptation, and gives awareness of the head and body in the environment. Individuals with

CHARGE syndrome have been documented to have colobomas of the eyes and impairments in the ability to process visual information (Blake & Prasad, 2006). The vestibular system consists of structures in the inner ear, otoliths and semicircular canals, that take in information about head position and movement (Haibach & Lieberman, 2013). Individuals with CHARGE syndrome often have underdeveloped or missing semicircular canals, involvement of cranial nerve VIII, and difficulty processing this information (Brown, 2003). The somatosensory system is composed of various sensors or input mechanisms through touch, pressure and stretch of the joints, muscles and tendons. Proprioception is part of the somatosensory system that provides information when an individual is working against resistance or against gravity (Brown, 2006). Individuals with CHARGE syndrome often have low tone, decreased strength due to impaired muscle length and muscle imbalances, and abnormal (too much or too little) joint mobility. Information from the sensory systems is gathered and processed in the brain stem, resulting in appropriate motor responses (Hall, Umphred & West, 2007). An appropriate balance response could be a small ankle movement, a large hip movement, or taking a step to prevent a fall. An accurate motor response starts with accurate sensory information. When these systems are impaired, balance is a daily struggle. Movement facilitates growth and development. From birth onwards, movement experiences stimulate the vestibular and somatosensory systems (Benabib, 2004). The infant moves its head from side to side to clear its airway. Proprioceptive input occurs during kicking against the surface while it's resting on a parent's chest or in its carrier. Visual and hearing impairments limit the child's curiosity to explore his or her environment, and therefore, decreases the motivation to move. Additionally, children with CHARGE syndrome are deprived of early movement due to long hospitalizations for medical issues.

### **Motor Learning and Balance**

As children with CHARGE syndrome develop, it is important that their balance is challenged so that they have opportunities to enhance their sensory experience and practice motor responses. Movement and balance experiences will allow these children to know the strengths and limits of their own visual, vestibular, and somatosensory systems (Benabib, 2004). It will also allow them to learn how to adapt and compensate for compromised sensory systems. Motor learning will not occur without motor challenges (Gordon & Magill, 2012).

A typically developing child who is learning to walk will rock side to side, attempt to let go of supportive surfaces and fall. They will repeat this, and in the process make slight adaptations to be more successful (Gordon & Magill, 2012). The child uses his eyes to explore the environment, including changes in the surface of the ground, or will learn that the sensation in their feet will tell them how to adjust to obstacles. This process is the same for children with CHARGE syndrome. The most important

aspect is that the more motor experiences these children have, the more effective they will become in using their residual vision, vestibular sense, and proprioception. Parents, caregivers, and clinicians may observe certain 'behaviors' as the child is developing due to anxiety or insecurity related to balance. A child who twists his legs around himself might be seeking proprioceptive information as to feel more secure about where his body is in space (Brown, 2006). A child lying on the ground, might be trying to stabilize himself as to be able to use his eyes more effectively (Benabib, 2004). A student who has a hard time standing still might be shifting his body and head to gain as much proprioceptive and vestibular information as possible (Brown, 2006).

Balance activities may not be rewarding or fun when they are unreasonably challenging. With the goal in mind of helping these individuals to improve motor skills, the physical therapist needs to create motivating and rewarding opportunities. The following recommendations will guide physical therapists in thinking about how to approach a child with CHARGE syndrome.

### **Recommendations**

- 1) Evaluate and determine the sensory needs of the child. A sensory program or sensory routine may need to be the first step in the session. A consult by an experienced professional, such as an occupational therapist, is a valuable tool.
- 2) Know and use the child's most reliable communication method: photos, tactile symbols, sign language, tactile sign, or speech. Speaking with the family, classroom teacher and/or speech therapist will assist in knowing this information. This will allow the child to develop a relationship with his physical therapist, and gain trust.
- 3) Everyone working with the child should know the specific behavior program as well as the academic and motor goals. Consistency and a team approach are key components to guiding the child toward success.
- 4) Create a consistent session routine with clear expectations. A schedule of the activities within the session can be helpful. It will also give the child the opportunity to anticipate the activity. The child will also need a consistent routine for transitioning to and from the physical therapy sessions.
- 5) Allow the child to explore within safe parameters. Constant physical and verbal cues can overwhelm the child. Provide one clear instruction or goal, allowing the child to focus, and give him time to react.
- 6) Give the child the opportunity to participate in activities that will allow adaptation and multiple repetitions to be successful (Gordon & Magill, 2012). For example, walking on grass, roller skating, or using a standing scooter will allow repetition of weight shifting and balance responses. Girardi (2011) shows various functional activities that challenge the balance system.
- 7) The child needs to know that they are successful. Using praise and providing activities that give innate feedback can be very successful for children with CHARGE syndrome. The goal is to instill comfort and confidence in the child. Maintain reasonable expectations and allow for slow progress.

- 8) Due to poor vision, low tone, decreased postural strength and endurance, children and young adults with CHARGE syndrome are at risk for orthopedic issues. The child's seating in the classroom and home should be assessed. A supportive foot surface and armrests provide a good base of support to improve postural alignment. Visual materials should be presented in the student's visual field. Slanted or elevated surfaces can be beneficial in preventing a collapsed forward posture.
- 9) Provide the child with the opportunity to change positions (i.e. standing, walking, sitting on a ball, etc.) every 15-20 minutes if they appear to be having difficulty focusing on the activity or task. This will change the child's arousal level, and give opportunity for different postural muscles to activate.
- 10) Yoga provides a child who has low tone, balance, strength and coordination deficits, with proprioceptive input through various poses that can improve body awareness and strength. It also gives the child a routine to follow that is enjoyable, and can be done as a group to encourage socialization.
- 11) Many individuals with CHARGE syndrome develop a flexed forward posture. Activities that involve weight bearing through the arms for upper back, abdominal, and arm strengthening should be initiated early in an attempt to prevent postural weakness that may occur. The child should have regular follow-up with an orthopedist or physiatrist to monitor skeletal structure, especially in the spine, hips, ankle and feet.
- 12) Like many typical children, there are multiple factors including medical complications and guarded lives that limit a child with CHARGE syndrome to experience the world. They should be given opportunities to explore, make mistakes, and learn from those mistakes. As the child with CHARGE syndrome gains skills, he or she will be able to participate more at home, school, and the community with confidence.

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## **Country news**

### **Nalaga'at Theatre Production was a hit in Perth, Australia**

As part of the recent 'Festival of Perth' in Western Australia, Israeli company Nalaga'at (the only deafblind theatre company in the world) brought their 'sell out' show to Perth. The Nalaga'at Deafblind Acting Ensemble was founded in order to integrate people who are deafblind into the community, promote their needs and aspirations and provide them with the opportunity to express themselves in a way that is meaningful to them.

The show "Not for Bread Alone" has been seen by over 700,000 people worldwide and has contributed to raising public awareness to the talents of people who are deafblind and promoting the universal values of solidarity, mutual respect, tolerance and coexistence.

Senses Australia clients and staff were very fortunate to attend this unique performance. The theater had an audio loop for clients that were hard of hearing as well as provisions for audio description and captioning. Post-performance, the actors and their supports generously shared their stories and skills with local people who are deafblind, as well as to some individuals who had flown interstate just to see the performance and participate in the workshop.

During the workshop different communication modes were enlisted and supported to ensure that participants from different sides of the world, and with different communication modes, communicated freely and enthusiastically with each. It was a unique experience to witness the multiple levels of communication at work including: Australian sign language, Russian sign language, hand-palm alphabet, tactile sign language - hand over hand, tapped braille, Israeli sign language, Deaf relay interpreting and spoken language in Russian, English and Hebrew.

Comments from participants included:

"Wow, what an experience. I especially loved the workshop with Nalaga'at. We had a ball"! Adina Tal, the Nalaga'at art director, has managed to create a way for people to connect regardless of language barriers and sense barriers. In doing so she has

created a close-knit little community that is happy to connect and share their joy with the rest of the world”.

“I had the great privilege of being involved in a workshop run by Adina. I am sure the actors provide inspiration where ever they go all over the world. I loved the exercises where we had to put our arms up and touch the person’s hands in front of us; this aptly illustrated the importance of touch to deafblind people, I felt so connected. They were like a breath of fresh air and I was very happy, I will never forget meeting them “

We would like to offer a huge thank you to the Nalaga’at troupe for being so generous with their time, talents and friendship. Their performance received rave reviews from critics and it significantly raised the profile of deafblindness in the Western Australia deafblind community. You came and shared a unique experience with the West Australian Deafblind Community and we are truly grateful.

**Karen Wickham**

**Senior Social Worker and Deafblind Consultant ([karen.wickham@senses.org.au](mailto:karen.wickham@senses.org.au))**

**Senses Australia ([www.senses.org.au](http://www.senses.org.au)). (Senses Australia is a small corporate member of DbI)**

## **Australian conference update**

### **9th Australian National Deafblind Conference – Down Under in Sydney**

New South Wales Ageing, Disability and Home Care (ADBC) CE Jim Longley officially opened the 9th Australian National Deafblind Conference before 100 delegates and interpreters from around Australia and New Zealand in spectacular Sydney on 7th June 2014.

Forsight Australia Board Chairman Frank Deane thanked Jim Longley and welcomed all delegates, interpreters and volunteers to this exciting 2-day Deafblind Conference held on 7th and 8th June 2014 at the Mercure Central Hotel in Sydney Australia.

Trish Wetton CEO of Host and Sponsor Forsight Australia and Chair of the Conference committee joined with co-sponsors Able Australia, Senses Australia, Conexu Foundation, the Deaf Society NSW and Community Relations Commission and Australian Deafblind Council (ADBC) to ensure the conference was fully inclusive. Trish thanked volunteer Committee members Janne Bidenko and Juanita McLeod DeafBlind Association (NSW) Inc and Rebecca Dunkley of Guide Dogs NSW/ACT.

Delegates, Deafblind adults and their carers/interpreters created an atmosphere of energy and passion throughout the conference, at presentations, workshops, at the plenary sessions and socializing in the dining room.

The main theme of the conference, "Access to my World" drew many excellent Abstracts from professionals, disability workers, family members and service providers. Session themes included Advocacy, Communication/Technology, Early Intervention, Support, and Service Provision, Social, Recreation, including Interactive sessions were all chosen to encourage presenters to embrace the topics and address the isolation that can cut people who are deafblind off from their community and families.

This Conference theme reflected a message from the writings of Inger Rodbroe and Marleen Janssen on Communication and Congenital Deafblindness: "Vision and hearing are not only important for establishing and developing interpersonal relationships. They are also the main motivating factors for being interested in the world and for making the world coherent and meaningful".

Keynote Speakers Sven Topp, Sharon Barrey Grassick and Steven Ripley presented on Haptic communication and Interactive communication.

The social highlight of the 9th Australian National Deafblind Conference was the conference dinner held in the Grand Central Ballroom. Inspirational presentations by Forsight Australia Ambassador David Hall OAM, the President of Deafblind NZ Incorporated12 – Merv Cox and Phil Harper who launched Conexu were enjoyed by all. At the end of the Conference, a special highlight was a video message on the European Rubella Network, sent to Sydney Australia by Joff McGill with an invitation to contribute stories to this Rubella Network.

Trish Wetton

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## **Canadian Deafblind Association (Ontario Chapter)**

### **Launches On-Line Learning Courses**

Canadians feel very strongly about intervenors and the success of their intervention methodology program towards improving the quality of life for persons with deafblindness in Canada. It is however, not always easy to locate staff with the specific education and training to provide the services to a growing population of people with this disability. To increase capacity based on the demand for this specialized knowledge, the Canadian Deafblind Association (Ontario Chapter) developed a series of online courses to provide intervenors in Canada (and around the globe) with additional opportunities for professional development. The topic areas of the courses arose from the work of a focus group that included intervenors from a variety of working environments.

To date, the following four courses have been developed.

1. Deafblindness and the Role of the Intervenor. This 8-module course defines deafblindness and its impact on an individual, discusses the different types of vision and hearing loss, and introduces the key components as well as the philosophy of intervention. It is a pre-requisite for all other online courses.

2. The Role of the Intervenor in Health, Wellness and Aging. This 8-module course addresses the knowledge and skills Intervenors require to appropriately adapt and implement intervention with individuals who have complex medical needs and/or who are aging. With this knowledge, intervenors are better able to support individuals who are deafblind in developing and maintaining a healthy lifestyle.

3. The Importance of Planning in the Role of the Intervenor. This 10-module course provides an in-depth look at different strategies used when planning with an individual who is deafblind. The course also addresses how planning helps to ensure a holistic, person-first approach to programming. Participants will have an opportunity to apply their knowledge through the use of case studies highlighting a variety of situations.

4. The Role of the Intervenor in Conceptual Development and Communication. This 10 module course focuses on the vital role that intervenors play in supporting an individual's conceptual development. The importance of linking communication with conceptual development will be highlighted. The differences between skill development and concept development will also be addressed.

As part of the development process when creating these courses, CDBA Ontario Chapter asked the George Brown College (GBC) Intervenor Program to provide academic oversight regarding the content of the courses. As a result, successful completion of the courses on Health, Wellness and Aging and on the Importance of Planning will allow those pursuing a GBC Intervenor (for Deaf-Blind Persons) Program diploma to apply for a "Prior Learning Assessment & Recognition" that may lead to an exemption". Successful completion of these two courses can also be applied to the CDBA Ontario Chapter Certificate in Congenital Deafblindness, developed in partnership with George Brown College.

The courses are offered in the semester format: Winter, Spring and Fall. The course "Deafblindness and the Role of the Intervenor" is offered each semester since it is a pre-requisite for the other three courses, which will be offered on a rotating basis. The online program began in January 2014. The tuition fee for the courses varies, depending upon the length of the course. Check out the website ([www.cdbaontario.com](http://www.cdbaontario.com)) for further details about registration for courses, course fees and payment options.

In addition to these courses, CDBA-Ontario is in the process of creating two additional online courses: Methods & Techniques and Calendars & Experience Books, which will be available soon.

## **The 7th Spirit of Intervenors Symposium**

Several hundred intervenors descended on the Best Western and Lamplighter Inn, London Ontario, March 03-05, 2014 to participate in the 7th Spirit of Intervenors Symposium titled: 'Collaborating and Sharing Ideas'. This annual event, which represents the largest gathering of intervenors anywhere in the world, was hosted by the Deafblind Coalition of Ontario (DBCO). The DBCO is a network of individuals and organizations dedicated to the sharing of information and the promotion of awareness of deaf-blindness and intervenor services in Ontario, Canada. The Canadian Deafblind Association, Ontario Chapter, was this year's lead agency. The symposium featured two international keynote speakers from the field of deaf-blindness: Joe Gibson, and Robbie Blaha and numerous other speakers connected with deaf-blindness, accessibility, communication, occupational therapy, yoga, humour in the workplace, inspiration, etc.

Dr. Joe Gibson is the Outdoor & Physical Activities Co-ordinator with Sense Scotland, headquartered in Glasgow Scotland. Robbie Blaha (M.Ed.) has many years of experience in the field of deaf-blindness as a classroom teacher, itinerant teacher and consultant. She works with the Texas Deafblind Project at Texas School for the Blind, Austin Texas.

Joe Gibson's keynote "Outdoor Activities with People who are Deafblind", inspired all those in attendance to remember that outdoor experiences are not only learning opportunities and an opportunity for exercise, but also just plain fun.

Robbie Blaha's brought tears to eyes, and brought everyone together with the message of "Intervenors as Ambassadors" in her keynote. She discussed how intervenors are vital in the process of bridging two distinctly different worlds.

Of particular note among the other guest speakers was Megan McHugh, a Toronto area technology instructor, sports enthusiast, and woman who is deaf-blind<sup>2</sup>. In one presentation, Megan informed the audience with a witty approach to "Sports and Recreation-an Adapted and Accessible Experience". She discussed the challenges she has had to overcome as a deaf-blind person, trying to remain an active participant in her favourite sports - skiing, tandem biking, hockey and baseball. In another presentation, Megan explained how the iPad has created "A New World of Access to Communication and Information for Persons Who Are Deaf-blind".

Apart from these speakers mentioned, attendees had the choice of other unique and information packed workshops including grief and loss, sexuality, pharmaceutical intervention, yoga, emergency intervention services, orientation and mobility, sensitivity and diversity, personal experience with cochlear implants, accessibility, sensory exploration and organizational connectivity, etc.

The sensory experience dinner pushed everyone out of their comfort zone by giving them the opportunity to dine in the dark. Blindfolded attendees had to navigate the table settings, cut and eat their food, as well as try and maintain conversations with music playing. The night was rounded off by the multi-instrumental sounds of Jamie Williams<sup>3</sup> and his one-man band.

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## **DeafBlind Ontario Services celebrates 25 years**

DeafBlind Ontario Services is celebrating 25 years as one of the largest not-for-profit organizations in Ontario providing Intervenor, residential and other specialized services to individuals who are deafblind in communities throughout the province of Ontario, Canada. To celebrate our 25th anniversary, we chose a theme that was inspired by the clients we support: 'A simple touch leads to endless possibilities.' Thank you to our Founding Members: Gerry and Dorothy Brogan, Michael and Adrienne Caruso, Lynne Faltash, Steven Gaylord, William and Carol Hurtick, Charles Kelliher, Dorothy Wilcox and Connie Southall for your perseverance and tenacity 25 years ago.

These families looked at many alternatives and readily knew that their children's special needs required a unique type of adult living. "We embarked on a special journey to find answers – which led us on a very long and winding path to get to where we are today", said Adrienne Caruso, parent.

Twenty-five years ago, a group of parents worked together to convince the Ontario government that their children needed specialized support in a community setting after graduation from the residential school they attended for deafblind children. They educated the government about deafblindness and what Intervenor were. Their advocacy efforts paid off! When the organization Independent Living Residences for the Deafblind in Ontario (ILRDBO) was born in 1989, three homes were established with three individuals with congenital deafblindness residing in each location.

Toward the end of 2007, ILRDBO changed its name to DeafBlind Ontario Services. Today, DeafBlind Ontario Services supports adults who are deafblind across the province through our Residential Services and Community Services, both fostering independent living skills through specialized support.

Our mission is to support individuals who are deafblind to live and thrive within their communities. Over the last quarter of a century, DeafBlind Ontario Services has created 26 homes in Ontario. From those initial 9 individuals, we now support 59 in both residential and community services across the province.

As part of our 25th year, we created an infographic to highlight the disability of deafblindness and our 25 year history. We look forward to what the next 25 years brings!

## **Living Proud and Giving Back**

For decades, people have made donations to causes and campaigns that are close to their hearts. Some give in very public ways – running to raise money, attending black tie fundraising galas, campaigning door-to-door, or championing a cause with

a social media campaign. Others do their good more quietly, making behind-the-scenes contributions that help strengthen their community. One such individual is Toronto's Bing Chen.

Bing embodies a spirit of gratitude by giving back to the Canadian Helen Keller Centre (CHKC) – the organization that provides him with services to support him both in his work and daily life. Knowing more about Bing will help to illustrate this giving spirit and how CHKC has been of assistance on his life's journey.

### **Bing's Story**

Originally from China, Bing's hearing loss was not discovered until the age of two. Doctors told his parents he would benefit from a cochlear implant, but his mother declined and Bing learned sign language.

As he got older, Bing started to notice he was losing his vision as well. "At night when I was playing basketball with my friends it would be really hard for me to find the ball," said Bing. "I didn't think anything of it. I was just patient with myself."

Bing attended the Metro Toronto School for the Deaf (MTSD) after moving to Canada from China at the age of 12. An eye doctor's exam recommended by MTSD revealed Bing was losing his peripheral vision and that he had Usher Syndrome, a condition characterized by hearing loss and progressive loss of vision. "They told me that as I got older I would continue to lose my vision and eventually become completely blind. I was really scared. I didn't know what to do," he said.

With support from CHKC, Bing knows he can continue to learn skills that will become important as his sight worsens. So far, he has participated in Braille classes, cooking clubs and a workshop on safety in the community. Now 22 years old, Bing has also learned how to use a white cane while travelling. His ability to travel independently is helping him succeed in his first-ever job as a stocker with the Target Corporation in Toronto.

Literacy training with CHKC instructor David Hamen is also playing a big role in Bing's workplace success. David is university educated and, like Bing, is deaf. This is a significant asset because the two gentlemen communicate via American Sign Language (ASL), which is their first language, and David can hone in on the exact kind of literacy Bing needs because he also uses ASL for communication.

### **On Target**

Bing has been involved with CHKC for two years and, for the past nine months, has met with David for 1.5 hours every week. Originally, general literacy was the focus of these one-on-one classes. In the fall of 2013, Bing's hiring by Target to stock shelves and assist with merchandising in the back room shifted the emphasis of his class work. David's instruction to Bing now also includes a variety of workplace literacy issues, including understanding memos posted on staff bulletin boards and signs in the back room. In addition, David works to help Bing understand Target's workplace policies, the company's vision and goals, and best practices for communicating with colleagues.

“Bing and I work on finding ways to communicate with different words he learns,” explains David. “Sometimes we focus on communication strategies and look at solutions and ways to avoid any misunderstandings.”

After approximately five months on the job, Bing is enjoying his work, even though he finds the early start time challenging.

“Bing travels to work on public transit using his white cane. He starts at 4 a.m. and works until the early afternoon,” said Mélanie Gauthier-Perley, Training Coordinator for CHKC. “During his first month or so on the job, Bing attended work with an Intervenor. This specially trained professional acts as the eyes and ears of a consumer like Bing and provides information about the environment and surrounding circumstances. CHKC’s support makes it possible for Bing and other individuals who are deaf-blind to succeed in meaningful employment.”

“Working with Bing is a lot of fun,” adds instructor David Hamen. “He tells me how much he really loves his job at Target. He shows a lot of enthusiasm for his job and respect for his co-workers. We discuss how sometimes his job can be a challenge when it comes to communicating with his team members. As some do not know ASL, they have to find ways to communicate with each other as a team.”

Target reports that Bing’s hard work is paying off. “Bing has proven himself to be a reliable member of our team and is dedicated to consistently improving his performance,” said Joshua Gordon, Executive Team Leader – Human Resources for Target at Centrepont Mall.

### **Giving Back**

Bing is being supported by CHKC to better understand his job. As a result, he is a proud contributor to his community and a proud supporter of the Centre.

“Without any fanfare, Bing regularly shows up with supplies for the Centre – many times with donations of coffee and tea to be enjoyed by fellow consumers who are participating in our programs and receiving services from CHKC,” explains training coordinator Mélanie Gauthier-Perley. “Bing’s amazing and ongoing generosity is a reflection of his pride in CHKC and desire to give back to the deaf-blind community. His contributions and acts of kindness make such a big difference and we are extremely appreciative of his support.”

“I am proud to work with Bing. He is amazing,” adds David Hamen.

Indeed, Bing is a wonderful example of the giving spirit that has helped to build CHKC into a vibrant organization for the deaf-blind community.

Prepared by Christine Payne on behalf of the Canadian Helen Keller Centre  
[www.ckhc.org](http://www.ckhc.org)

# **News from Partner Programs of Perkins International Latin America & Caribbean**

## **CORPALIV - Corporación de Padres y Amigos por el Limitado Visual - Santiago, Chile**

CORPALIV is a nonprofit organization, created in 1992, that provides support to parents of children with visual impairments and multiple disabilities. In 2003, CORPALIV founded the 'Jan Van Dijk Special School', which is oriented to provide services to students who are deafblind or have multiple disabilities. They provide services from infants through adulthood.

CORPALIV special school follows Perkins International guidelines on curriculum, working with families and facilitating ongoing training for teams. Actually, one of the mothers who has a child participating in the CORPALIV program, has become a leader in the deafblind field in Chile.

With the purpose of giving meaningful experiences to students and their families, CORPALIV has developed such 'hands on' workshop programs as food preparation, organic gardening and mosaic art.

The following photos represent these three workshops:

### **The Organic Garden Workshop**

As the photos demonstrate, the students participate in different activities related to growing and selling plants. CORPALIV intends that this activity can be incorporated at home as a way of families supporting their children at home and in the community.

### **The Food Preparation Workshop**

One of the many benefits of this workshop is the opportunity for the participants to gain more personal autonomy.

### **The Mosaic Art Workshop**

There are some opportunities for the students to sell the creative products from this workshop. This also allows CORPALIV to obtain funds to acquire new materials to further explore the interests and abilities of their students.

### **Music Therapy**

Since last year, CORPALIV has begun a Music Therapy program. While providing the students with a rich but controlled music environment, the main goal of this program is to encourage communication and expression of emotions by the students through non-verbal strategies.

Listening to sounds and music, and encouraging movement and corporal self-expression are the core intentions of this therapy. Students who are deafblind appear to greatly enjoy this experience.

This Music Therapy has also been extended to the families through providing a valuable space dedicated to individual's self-expression, self-care and personal development.

In addition, this music therapy program is offered to CORPALIV professionals to allow them to acquire musical skills that they can implement in their classrooms and other programs.

Submitted by: Graciela Ferioli, Representante Regional, Perkins Internacional América Latina  
Córdoba Argentina ([www.perkinsla.org](http://www.perkinsla.org))  
(Perkins Internacional América Latina is a small corporate member of DbI)

## **The beginning of knowledge about deafblindness in Ethiopia**

### **A collaborative project between the Ethiopian Sign Language and Deaf Culture Program at Addis Ababa University and Royal Dutch Kentalis**

The knowledge of Deafblindness is a new phenomenon in Ethiopia. This is the reality despite the fact that Ethiopian National Association of the Deafblind (ENADB) has been officially established in the country for the past 8 years. The association received its legal certificate from the Federal Ministry of Justice, as per the new civil society proclamation, in the middle of 2006.

While it is now well understood that people with Deafblindness lived in the country before the establishment of the association, the overall lack of knowledge about Deafblindness prevented the provision of appropriate intervention.

The association was established through the commitment of Deafblind people, in particular those with acquired Deafblindness, who took the initiative to establish the association. When they thought about establishing their association, they realized that the first challenge was to find Deafblind people throughout the country. For various reasons, people who are Deafblind in Ethiopia are hidden at home.

During the early days of the organization, ENADB attempted to study the situation of people who are Deafblind throughout the country. They learned that most lived in such inhumane conditions as: children being tied-up at home in their beds; older individuals placed in corners of their homes and others placed in darkened rooms. The Federal Ministry of Education of Ethiopia provides a lot of attention to children in general including those with special needs to achieve the Education for all and Millennium Development Goals. The Ministry has been working to develop strategies for Special Needs Education. One of the strategies that the Ministry implemented was to train staff members in all levels of Special Needs Education. Currently six Colleges of Teacher Education provide diplomas in Special Needs Education and five Universities provide Bachelor in Special Needs Education in Ethiopia.

Despite all these good efforts from the Ministry of Education, they failed to include issues about Deafblindness. The people trained in the Special Needs Education Programs have inadequate or no knowledge in Deafblindness. A special course in Deafblindness had not been offered. In addition, there is no school or special centre in Ethiopia that accommodates children who are Deafblind to provide them appropriate intervention.

### **Progress Being Made**

On the brighter side of the Deafblindness issue in Ethiopia has been the development of an Ethiopian Sign Language in 2008. This positive development was through the Ethiopian Sign Language and Deaf Culture Program Unit of the Department of Linguistics in Addis Ababa University, a unique program with focus on Sign Language and Deaf studies.

After the establishment of the program, the Ethiopian National Association of the Deafblind (ENADB) approached the Ethiopian Sign Language and Deaf Culture Program Unit and requested professional support for the association. This was a shocking question for the program since the professionals had no knowledge about Deafblindness to undertake this professional support.

### **Establishing a collaborative project with Kentalis**

This led the Ethiopian Sign Language and Deaf Culture Program to search outside Ethiopia for assistance to obtain knowledge about Deafblindness. After some efforts, we found Royal Dutch Kentalis. We contacted the Kentalis International Foundation of the Royal Dutch Kentalis and explained the need for knowledge in the area of Deafblindness in Ethiopia. They accepted the request to assist us to develop our knowledge in the area and agreed to a collaborative project.

A collaboration project entitled 'Deafblindness: Theory and Practice in Ethiopian Context' was designed together with Kentalis International and formalized through a four year funding agreement, 2011 through 2014.

The overall goal of the project was that Deafblind people in Ethiopia (congenitally Deafblind people as well as people with acquired Deafblindness) and their families receive effective support from professionals to ensure they fulfil their potential.

The project was designed to be implemented in three phases over the four year period.

Phase I, featured an Introductory Training Course on Deafblindness, which took place at Addis Ababa University 12th December to 16th December, 2011. Topics in this introductory training included: introduction to Deafblindness, personal experiences with people with Deafblindness, situation with Deafblindness in Ethiopia, orientation and mobility, interaction & communication, services in other countries and future plans for the project. Twenty-two participants were involved in this introductory training - 8 lecturers from Addis Ababa University, 6 teachers from the Ethiopian National Association of the Deafblind, 3 teachers from schools for the

Deaf, 2 teachers from school for the Blind, 1 participant from Ethiopian National Association of the Deaf, and 2 students of Addis Ababa University.

Phase II activities took place 2012 through early 2014.

Year 2012 included a 'Train the Trainer' Course on the Basics of Deafblindness and a Training Course on the Assessment of Deafblindness.

The Train the Trainer Course on the basics of Deafblindness took place over a nine day period and included such topics as: what is Deafblindness?, causes of Deafblindness, communication, information acquisition & processing, daily life skills, development of social interaction, and teaching strategies. Twenty three participants were in attendance representing the following: Addis Ababa University, Teachers from Schools for the Blind, Deaf and ENADB, Kotebe College of Teacher Education, Community Based Rehabilitation organizations.

The Assessment of Deafblindness Course included: General information about Deafblindness, syndromes, vision and hearing, child guided strategies, etc.

Twenty-one participants were in attendance for the four day course, representing the same organizations mentioned above, but with the addition of specialists in audiology and ophthalmology.

Years 2013-2014 included a Training Course on Acquired Deafblindness and a Training Course on the Basics of Deafblindness delivered to Community Based Rehabilitation workers.

The Acquired Deafblindness Course focused on introduction about Deafblindness including the various causes; life stories and personal experiences; communication and interaction; and life adjustments. Twenty three participants and four assistant trainers attended this four day course representing similar organizations as mentioned for previous courses.

The final training course offered by Kentalis was the six day course, Basics of Deafblindness for Community Based Rehabilitation Workers. The training focused on Deafblindness general theory, personal experiences, safety, contact and interaction, communication, independence, etc. A total of 24 participants and 5 assistant trainers participated from a variety of NGO's working in the area of Community Based Rehabilitation.

During each training session, sign language interpreters for Deaf participants, interpreters/interveners for Deafblind participants and translators for participants who need Amharic translation were used to facilitate the communication between the trainers and the trainees.

During the period of Phase II, a consultative meeting between experts of Kentalis International and the research team from Addis Ababa University were held in early 2013. Through discussion, the participants decided that, critical to implementing the program, a research project was essential to carry out a 'Baseline Survey to determine the Status of Deafblindness and the Deafblind in Ethiopia'. As of this date, the survey has been completed and the results are ready for dissemination at future workshops.

Following the training involving experts from Kentalis International, we in Ethiopia are now implementing Phase III. Through the trained staff here in Ethiopia we are

disseminating knowledge about Deafblindness to disabled peoples organisations, social workers, community based rehabilitation organisations, parents, special educators and regular classroom teachers, hospitals, health workers, health extension workers, churches, community leaders, etc.

In addition, we are networking internationally through various activities. These include our mini-corporate membership of Deafblind International, attending conferences on Deafblindness (eg Lille 2013) and attending the Master study in Communication and Congenital Deafblindness at Groningen University.

Andargachew Deneke

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## **The Development of Services for People who are Deafblind in Hong Kong is Progressing**

The year 2013 was a special year for the Deafblind Service of Hong Kong as it commemorated the second decade of its services. The Hong Kong Society for the Blind has been actively involved in public awareness and providing rehabilitation training to the deafblind community. Our goal is to enhance the quality of life of persons who are deafblind through supporting them to live independently and maintaining their dignity while living in society.

The Resource Centre for the Deafblind offered Communicator Guide training courses for the first time in 2010 for the professionals working with the deafblind community, and for the people who are interested in deafblind services. The aim of these courses was to train individuals to be Communicator Guides for people who are Deafblind. Certificate Courses were offered in 3 levels - Basic, Intermediate and Advanced. The courses covered 50 contact hours and 20 practicum hours of 'real life services' delivered to the deafblind individuals. A total of 120 individuals completed the courses and received certification.

### **Pilot Project - Communicator Service for the Deafblind**

People who are deafblind in Hong Kong have long wished for a Communicator Guide service like that offered in Western countries. While some of these individuals already live independently, they want to have an 'intermediary' to communicate and guide them from time to time. Their dreams finally came true in 2013!

With much gratitude and appreciation to the S.K. Yee Fund for the Disabled, the Hong Kong Society for the Blind started a 3-Year Pilot Project on a Communicator Guide Service for people who are deafblind in Hong Kong. Communicator Guides can offer escort and guide services for people who are deafblind to assist with their

personal daily living, shopping, hospital visits, leisure walks in the park, participating in social activities, etc.

**The objectives of the pilot project are:**

- 1 To train a group of communicators to provide support to people who are deafblind who have difficulty communicating.
- 2 To provide people who are deafblind with a communicator guide service to improve their quality of life and prevent these individuals from being isolated from the general society.
- 3 To arouse public awareness to the needs of people who are deafblind in Hong Kong.

In a quick review of the service in the first year, we offered 15 public awareness training programs to more than 400 students and the general public. The number of communicator-guide services provided by the trained communicators to the individuals who are deafblind living independently in the community was approximately 50 times last year.

We intend to expand the communicator guide service in the near future to: a) elderly persons who are deafblind and living in homes for the elderly, and b) to those persons who are deafblind with multiple disabilities.

**Contact Us**

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**Rev. Dr. Cyril Axelrod**

**awarded the Officer of the Most Excellent Order of the British Empire, OBE**

As the Honorary Consultant of Deafblind Services for the Hong Kong Society for the Blind since 2008, Rev. Dr. Cyril Axelrod's distinguished dedication to the development of deafblind service in Hong Kong was recently recognized in a significant way. He is the first deafblind person to have received the Officer of the Most Excellent Order of the British Empire, OBE.

Rev. Dr. Cyril Axelrod, who has Usher's Syndrome, was born deaf and later became blind. Through his understanding of the special needs of people who are deafblind, he volunteered to assist in developing the Chinese tactile sign language. He has maintained close contact with of the Hong Kong Society for the Blind in setting up their services since 1990s.

Rev. Dr. Cyril Axelrod served as a pioneer in developing an effective communication method for Hong Kong's deafblind community through making significant

contributions in the development of the Chinese Tactile Sign Language. Rev. Dr. Cyril Axelrod also contributed his precious experience towards developing a unique Orientation and Mobility guiding method for people who are deafblind.

With his assistance, the services for people in Hong Kong who are deafblind have expanded significantly. Rev. Dr. Cyril Axelrod was instrumental in the drafting the curriculum for the Communicator Guide Certificate Course that began in 2010. He serves as the demonstrator for orientation and mobility guiding in the video presented at the three levels of the certificate course.

Rev. Dr. Cyril Axelrod, being deafblind and with excellent communication skills, acts as a positive role model for independent living. There is no other person in the field in Hong Kong who stands out as inspirational as Rev. Dr. Cyril Axelrod. In addition, Rev. Dr. Cyril Axelrod extended his voluntary service to South Africa in 2012 through establishing the Cyril Axelrod Legacy Foundation (CALF) to provide training and support to the deafblind community in South Africa, the country of his birth.

The investiture ceremony was held on 22nd of November, 2013 by her Majesty Queen Elizabeth II at Windsor Castle, UK. The Queen encouraged Rev. Dr. Cyril Axelrod to continue his valuable work around the world helping deafblind and disabled people. Rev. Dr. Cyril Axelrod is determined to continue his mission to promote the 'gift of disabilities' to the world.

Contact us

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## **The Anne Sullivan Centre hosts its first Deafblind Awareness Day**

### **on the birthday of Anne Sullivan**

The Anne Sullivan Centre hosted the first ever Deafblind Awareness Day on April 14, 2014 in Sandyford, Dublin. We were honoured to have Fr. Cyril Axelrod OBE, as the guest speaker for our event, which brought people from various organisations across Ireland. Stalls from NCIB (National Council for the Blind in Ireland), DeafHear, and ASH Technologies were a few of the local organisations representing individuals who are Deafblind. The Centre, along with Deafblind Ireland, hopes to make this an annual event, as it is important to bring awareness to this unique and low incidence disability. The event was held on April 14 as this is Anne Sullivan's birthday and she was the inspiration for our Deafblind Centre and Services.

The Anne Sullivan Centre and Foundation are also excited to share news of a recent project, run by Laura English from the Centre. "A Study into Deafblindness in Ireland" was launched in late 2013 and the results of the survey are being analysed

and interpreted now. A survey on Deafblindness has never been done in Ireland so it is not known how many people in Ireland are Deafblind. As many countries have Census surveys it has been a learning experience for Deafblind Service Providers in Ireland. We hope to have the Research Project results this summer to share with Dbl International readers in the future.

Deirdre Leech and Heather Colson-Osbourne (info@annesullivan.ie)

Anne Sullivan Centre (www.annesullivan.ie) (The Anne Sullivan Centre is a small corporate member of Dbl)

Brewery Rd, Stillorgan, Dublin, Ireland

### **Theatre: a big adventure on the road to rehabilitation**

For several years, acting has been part of the adult deafblind services at the Rehabilitation Centre of the Lega del Filo d' Oro<sup>1</sup> in Osimo Italy. It involves every aspect of a rehabilitation programme: independence, communication, orientation and mobility, use of technology, recreation and interpersonal relationships, occupational workshop.

### **Not always an easy road**

One of the most difficult things for our guests - some of whom are deafblind and multisensory impaired but all of whom are blind, is to imagine another reality which is different from their own daily life experience.

Therefore, one of our objectives was to offer these individuals an opportunity to play a fictional role; with the requirement of respecting the timing, rhythm and contents of a simulated dialogue which is sometimes spontaneous. The choice of themes and the method of presentation are never pre-determined, but arise spontaneously from the participants during the weekly workshops. These performances take place in an area which is familiar to the guests allowing them to adapt immediately to their environment.

The creators of the 'theatre project' and the assistants and volunteers who work with them, are firmly convinced that the human imagination can overcome many intellectual, physical, sensory and emotional limitations. These guests are given this 'extraordinary opportunity' of acting to become 'characters' in roles which are different from those normally given to disabled people. Through this experience they demonstrate curiosity, a desire for growth and interest in learning new things.

### **"On stage" frequently.**

There have been many different shows organized. The most recent performance by deafblind people from the Lega del Filo d'Oro was 'The Tempest'<sup>2</sup> by William Shakespeare performed on 14 May in the theater 'La Nuova Fenice'<sup>3</sup> of Osimo. Our performance was preceded first by a production of the same play by the French disability group, the Cultural Association Lee Voirien.<sup>4</sup> The Association Voirien Lee

is a group of people with disabilities who together share and reinforce their common passions of theater and culture in general.

This performance on May 14, 2014 was the result of the European project IMAGINE MDVI5 (An inclusive forum to develop Movement, Action, Gesture, Improvisation, Negotiation and Expression of Multiple Disability Visually Impaired adults). The project started with the aim of developing and spreading theatre as a way to benefit multisensory impaired people. The partners were the Lega del Filo d' Oro (Italy), Lee Voirien (France), Royal Blind (Scotland) and SWW-Germany – see footnote 5.

“We are very happy with the work we have done”, says Patrizia Ceccarani, Director of the Rehabilitation Centre in Osimo. “This event to close the project has given us the opportunity to share the guidelines which all the partners collaborated to produce. We have used theatre in rehabilitation programmes at the Lega del Filo d'Oro with great results. This is why we continue to believe in it and to commit ourselves to it. I would like to thank all the assistants, educators and volunteers from the Lega del Filo d'Oro, because without their commitment none of this would be possible”.

During the closing ceremony, the website <http://imagine.sww-muenchen.de/> of European project IMAGINE MDVI was presented. This site is dedicated to theatre as a tool for rehabilitation and interaction among people who are multisensory impaired. The guidelines of the project, which offer advice, resources and materials for the professionals who work with MDVI theatre groups, were also presented.

The objective of the project is to challenge and, in many cases change, the perception of theatre to include actors with visual impairments associated with other pathologies (MDVI). The importance of theatre in each of the cultures was examined by looking at how each partner operates, by the sharing of ideas and by recognizing what they had in common. Through discussion and sharing of photos and films about their theatre experience, the partners showed they could work with the same methods and objectives even though they had users with different characteristics. A classic work was chosen for the project. Each partner adapted it to suit the needs of their own group of users. William Shakespeare was chosen because his works are dramatic, have a setting rich in sensory experiences and require emotional involvement. His works can also be adapted to different levels to suit the skills of the users.

### **The role of the volunteers**

Volunteers who take part in theatre work have a truly complex task. As well as being interpreter-guides, offering support for exploring the environment, they must be actors too to support the other actors. What the volunteers do in a scene is part of what the deafblind person does; their eyes and ears become the link with the audience. Taking a deafblind person onto the stage means guiding them, prompting them and acting with them. Most importantly, it means sharing the success of the show with them through a hug at the end of the show; applauding in the same way and making the public come alive by physically taking the deafblind person among

them. Theatre is words, people, society, poetry and history and is simultaneously lived by the actor and the audience.

This year the Lega del Filo d'Oro celebrates its fiftieth anniversary as an association offering support to the deafblind and multisensory impaired and their families. Its mission is to help its users to be as independent as possible, to combat their isolation, offer them better life conditions, re-integrate them into society and their families and restore their dignity. Today the Association has seven branches in different regions of Italy: at various centres at the headquarters in Osimo (AN), centres in Lesmo (MB), Modena, Molfetta (BA), Termini Imerese (PA) and local offices in Rome and Naples.

**For more information, contact Patricia Ceccarani, Director, Lega del Filo d'Oro Rehabilitation Centre ([ceccarani.p@legadelfilodoro.it](mailto:ceccarani.p@legadelfilodoro.it)); or the website: [www.legadelfilodoro.it](http://www.legadelfilodoro.it)**

## **Transition to adult life of youth with multiple disabilities and deafblindness**

**Latin America, 2013 – This document was prepared with the support of Fundación Once America Latina (FOAL) and Perkins International Latin America.**

**Authors: Buceta, Carolina (Argentina); Burges, Helena (Brasil); Ferioli, Graciela (Argentina); Laynes, María Graciela (Perú); López Masís, Rocío (Costa Rica); Romero, Silvia (Argentina); Rubiolo, Paula (Argentina); Soza, Áurea María (Argentina).**

### **Summary of the original document**

#### **Background**

The first draft of document about Transition to adulthood in Latin America was produced in 2008. The goal of this initial document was to share the guiding principles of services for young people with multiple disabilities and deafblindness in Latin America.

The document was distributed to families, professionals, educational institutions of all levels and modalities; governmental and nongovernmental organizations in different countries of the region, to serve as a basis to initiate or strengthen programs or services related to this population. From the feedback received by the readers of the initial document, the authors were motivated to meet again as a group and to make a second version, to strengthen the content and as well share some stories and best practices in Latin America.

The objective of this current document is to systematize the basic aspects of transition to adulthood, based on best professional practices in relation to young

people with deafblindness and multiple disabilities and their families, that can support the creation of public policy.

For a copy of the full document (in Spanish only) go to [www.perkinsla.org](http://www.perkinsla.org).

### **S's Story**

S is 18 years old and attends a state-run school in Argentina. He was clinically diagnosed with CINCA, also known as NOMID11 (Neonatal-onset multisystem inflammatory disease), and has visual and auditory challenges. This is a condition which becomes more complicated over time. Access to education and participation in a full life for S had once seemed unattainable! However, through a partnership between the special school and a primary school for adults, S now attends school like any other student in Argentina.

S has made significant progress over the years through his program of working on academics in the mornings and developing vocational skills in the evenings. He can read and write, uses the computer and is mobile with a wheelchair. He communicates with others using various communication symbols. His school encouraged him to participate in leisure activities. This has led to full community inclusion as he is engaged in swimming, winter activities like dog sledding and cross-country skiing, wheelchair-adapted riding, golfing, and sports competitions as well. S is a clear example that nothing is impossible.

### **A's Story**

A is 31 years old and was admitted into a program called 'Project for Future Life' in Mexico 10 years ago because of her visual and cognitive needs. The program helps young families and professionals plan their future based on their interests, desires, and dreams. A said her dream was to study, work, move independently, and have friends and family. A team of professionals began to develop a plan for her. With help from this program, A was trained on how to use a white cane; memorize personal information including names of people and streets; recognize everyday places, use public transportation, and identify visual, auditory, and tactile landmarks.

While the training enabled her to walk home independently, she could not remember the name of subway stations. Her team had to re-strategize. The solution: A should use a beaded bracelet and a pendant; every time the doors of the train opens and closes, she has to move a bead from one side to the other, indicating that A was going to pass a subway station. A should then wait until she arrives at the station that smells like onions; this indicates to her that she needs get off at the next station because it is near her home.

This strategy was a success and has opened a whole new world of possibilities for A. Currently she moves independently to and from work using the individualized plan developed for her.

Submitted by Graciela Ferioli  
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(Note: Gloria Rodriguez-Gil has been assigned as the new Regional Coordinator for Latin America and the Caribbean. She can be contacted at Perkins International, 175 North Beacon St., Watertown, MA 02472, tel 617-972-7359, fax 617-923-8076)

## **Diagnostic Team Deafblind: Person Guided Assessment**

**Trees van Nunen and Anne Schoone**

### **Focusing on strengths and potential in a dynamic way**

- What can my child hear and see and how does she/he use her senses in daily life?
- How can we stimulate our child's development?
- What kind of education or care does best fit the needs of my child?
- My child displays self-injurious behavior. What is the cause of it and what can I do to reduce this?
- Is there anything I can improve to my workplace, to be sure I can keep doing my job?

These are just some examples of questions that can arise concerning people with deafblindness or people involved with someone with deafblindness. Often, there is not that simple an answer to those questions. In many cases, specialized diagnostic assessment can provide information about what support is required.

At Royal Dutch Kentalis in Sint Michielsgestel, the Netherlands, we have a multidisciplinary diagnostic team that can help answer questions like these, by doing different kinds of assessment.

The Diagnostic Team Deafblind includes an ophthalmologist, an orthoptist, a psychologist, an audiologist, a speech and language therapist /communication expert and a physician with expertise in intellectual impairment. If required we can also add other specialists such as a psychiatrist, an occupational therapist or a physiotherapist. The assessments can be done by different members of the team, depending on the questions people ask.

In our diagnostic process, we use a methodology based on the diagnostic cycle described by Pameijer & Beukering, (2004). The diagnostic process is cyclical; after each phase of the process it is possible to go back to the previous phase. Once the whole cycle has been completed, the results can once again lead to a follow-up or

additional assessment. In these cases, a new cycle begins; sometimes directly and sometimes later?

At the very beginning when we see the individual during the initial Registration process, we collect as much information that we can about the person. Before we start the assessment, we develop a Strategy. We look at the information already available for the individual with deafblindness and examine the questions for assessment that have been asked. All the experts on our team advise which additional assessment would best assist the individual.

The Assessment process consists of an individual assessment, usually in combination with observations and interviews with the individual with deafblindness themselves or with other people involved with that individual.

After the assessment, all the observations and interviews are Integrated in a preliminary report. We discuss this preliminary report with all the team members, allowing each to give input from their own professional perspective. In this way we can draw a complete picture of the person's current situation including options to further develop their potential. Based on this comprehensive information, we complete the report along with a series of recommendations.

The report is then discussed (Advice) with the person with deafblindness and/or their family members involved with their care. Members of our team can either be involved in the individual's subsequent support program or we recommend alternatives where the necessary support can be found.

### **Challenges with deafblindness assessments**

Unfortunately, there are very few standardized tools to assess individuals with deafblindness. When using standardized tests, you often only assess what the individual cannot do, instead of determining what they can do now and what their capabilities might be. The goal of our team is to assess the strengths of every individual with deafblindness, because the deafblind person themselves give cues or directions for how they can reach their potential.

For individuals with congenital deafblindness, we often use a combination of development scales, standardized tests and 'hands on assessment'. We adjust these as much as possible to the person's sensory, physical and motor abilities. In 'hands on assessment', based on the procedure of Dr. Jan van Dijk (Nelson, van Dijk, Oster & McDonnell, (2009) and the Nordic Model for assessment (Anderson & Rødbroe, (2006), we follow the initiatives of the person with congenital deafblindness and use them to assess their own strengths. Since each individual with deafblindness is guiding (and is the guide), every assessment is completely different according to each individual.

For individuals with acquired deafblindness, we use parts of the standardized tests more often. When we use standardized tests, we adapt them to the individual needs of the person with deafblindness. We are very careful about the interpretation of results, because there is no standard group of people with deafblindness to compare to.

**Usher Team:**

“The added value for me is the way the Usher team operates. The different professionals really are one team and provide me with all the information I need about my vision and hearing”, stated a woman with Usher type 2.

An important section of Team Deafblind is the Usher Team. Because of the progressing character of Usher syndrome, it is important for individuals to get regular examination of visual functioning and ophthalmological conditions. We often hear from individuals with Usher that they experience a lack of knowledge about their condition and poor coordination among the different professionals involved in their regular care. To make it worse, they often have difficulty communicating with these professionals. This is why we started the Usher Team.

The main objective of the Usher Team is: to provide multidisciplinary assessment and advice to individuals with Usher and the people in their lives around them, including family members, educational staff, support workers, employers, etc. The advice provided by the Usher Team is usually focused on rehabilitation and psychological support.

For convenience of the Usher client, the team makes a plan with the individual to ensure that they travel to the team once for their entire assessment process. During this one visit, appointments are made with professionals for vision and auditory examinations, psychosocial well-being and for their overall advisory review. After the examination day, the individual is provided a clear report containing the results of the various examinations and service advice.

**CHARGE Team:**

“They listened to our story and put an emphasis on the potential of our child. This was new to us. We finally felt understood”, stated the parents of a 4-year old boy diagnosed with CHARGE.

The complex problems and lack of knowledge about the rare Syndrome CHARGE raise many questions among family members. Consequently a CHARGE Team was developed as part of Team Deafblind and the Medical Department of Kentalis. In the Kentalis CHARGE team, knowledge and experiences are collected and shared. We have created a place where people with CHARGE, parents and professionals can address their questions related to medical issues, development, communication and behavior.

At the moment, the CHARGE team primarily consists of two psychologists and a physician specialized for people with intellectual disabilities. To address specific questions related to CHARGE, a network of professionals from other disciplines (speech and language therapy, communication, ophthalmology, orthoptics, audiology, occupational therapy and psychiatry) is available on request.

Together with all the people involved with the individual with CHARGE, we take the steps to find out what services are needed to support the person with CHARGE.

**In summary the services of the CHARGE Team include:**

- Making observations and assessments to determine the strengths and potential of the person with CHARGE
- Providing information about CHARGE syndrome to family members, service providers and educational staff
- Organizing annual CHARGE family meetings together with the Dutch CHARGE family support group and the University Medical Center in Groningen

**Deafblindness Centre of Excellence: services and knowledge sharing**

Within Kentalis all facilities that focus on providing services to people with deafblindness are united in the Kentalis Deafblindness Centre of Excellence. The Diagnostic Team Deafblind is one of the teams comprising the Deafblindness Centre of Excellence. Together with our colleagues from the Treatment and Rehabilitation teams, we continue to look for opportunities to integrate diagnostics and treatment as much as possible.

An important activity of the Deafblindness Centre is knowledge sharing and learning. This is consistent with the mandate of Royal Dutch Kentalis as being a Knowledge Organization. As a result, exchanging information, skills and expertise among professionals outside of Kentalis is strongly encouraged. An example of one of our knowledge sharing activities was the visit by Dr. Jude Nicholas (clinical neuropsychologist, Statped Vest Resource Centre for Deafblind / Haukeland University Hospital, Bergen, Norway) to our organization this past March, 2014. During meetings with the Diagnostic Team and other experts we received new theoretical and clinical insights from Dr. Nicholas about dynamic assessment of cognition and autobiographical memory in the body-tactile modality. Part of the knowledge exchange included discussing ways of increasing our knowledge of neuropsychology. This inspired our team to make our future cognitive assessments even more dynamic. Dynamic assessment of cognition (Wiedl, Schöttke & Calero (2001), is a diagnostic approach in which specific interventions are integrated into assessment procedures to estimate cognitive modifiability. In addition of knowledge sharing, we also discussed ways for future collaboration. The visit with Jude was a starting point for us to evaluate our way of working in the long term in the Diagnostic Team Deafblind. We agreed that we should maintain the things we know are good, without losing the fact that we can improve as we gain new insight and knowledge.

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## Parents – active members of the multidisciplinary team in Romania

For over a decade, Sense International (Romania) has been organising, twice a year, network meetings for teachers working with deafblind and multisensory impaired children.

Such a meeting has taken place in Timisoara at the end of March 2014. The theme was one of great importance and interest: 'Parents and their essential role within the multidisciplinary team'. Because such a theme could not be approached in the

absence of parents (the key resources for specialists working with these children), we enjoyed the presence of two extraordinary parents who shared with the group their experiences; happy moments as well as the challenges they must deal with. Local authorities from Timis County were represented by Diana Bumbacila, special education inspector. She shared with the participants the fact that Timisoara is unique in Romania since early intervention for newborn babies with sensory impairments is embedded in the education system.

Cristiana Salomie, Director of SI(R), emphasised the importance of early intervention being embedded in the education system in all towns which have such Early Intervention Support Centres.

All the presentations from the specialists from Timisoara, Oradea and Iasi focused on parents and their involvement in the activities with the children. The meeting had special moments where participants asked questions, taking advantage of the presence of the two remarkable specialists from Timisoara: Dr. Florina Stoica, ophthalmologist and Dr. Dorinela Zalos, ENT specialist.

The event, attended by parents, special education teachers, early intervention workers, ophthalmologists, ENT specialists, physiotherapists and local authorities, was further proof that if there is collaboration among all these partners, wonderful things can be achieved for the benefit of children with deafblindness and multisensory impairments.

Timisoara is a model of best practice for early intervention in Romania. In 2013, 2,833 babies were screened for hearing at birth and 894 had their vision tested. From the results of the screening, 34 were included in the early intervention programme, receiving specialist support from SI(R) trained early intervention workers.

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## **A First for Thailand – Deafblind Camp, a Success for Both Students and Educators**

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Thailand reached a milestone this year when the first ever Deafblind Camp took place from March 15 to 23, 2014. Perkins International, the Christian Foundation for the Blind (CFBT), Ratchasuda College of Mahidol University, Suan Dusit Rajabhat University, Lighthouse Family and the International Society for Augmentative

Alternative Communication (ISAAC Thailand) organized this camp to provide opportunities for learning and socialization among children and youth who are deafblind with complex communication needs, as well as training for teachers in functional and literacy learning activities. Participants included seven deafblind students and fifteen teachers from six schools for the blind and one school for the deaf, three sign language interpreter students from Ratchasuda College, and one Perkins International educational specialist. Since communicating through tactile sign language has been identified as an area of weakness in schools for the blind, professionals were selected to ensure that each student would have one person who could sign with them.

Daily activities in the camp were designed to teach functional activities through using a consistent schedule and augmentative alternative communication via tactile sign language and symbols. Students learned to manage their daily routine, including self-care, washing their clothes, cooking main meals with teachers, picking vegetables to use for cooking and cleaning up together. They then had opportunities to choose from a variety of activities such as:

- Beading corner: making key rings, rings, bracelets, necklaces, etc. Both teachers and students learned new designs for jewelry making during the camp.
- Literacy corner: Oy used a slate and stylus for learning braille at school. She was very excited to use a Perkins brailier to type braille for the first time at the camp.
- Making snacks: juicing drinks from Pandan leaves, cooking steamed sticky rice with banana, preparing jelly using the fruits picked from the garden.
- Gardening: growing plants, watering, etc.
- Open activity: Misuko created a lift from her imagination.
- Shopping: Camp participants learned to create a shopping list and went to the local market near the campsite to buy items required for the camp. Through this activity, they learned the concepts of using and counting money and buying items via sign language, as well as enhancing literacy skills.
- Business entrepreneurship skills: Students opened a small store to sell desserts and other items they had made during the camp.
- Outing activities: going to the small river near the camp.
- Literacy skills by writing diary: Students learned braille through writing in a diary. They brought their diaries home with them to bring back memories of the camp.

After nine days, teachers and students alike gained knowledge in using a variety of communication skills, such as tactile sign language, objects, tangible symbols, large print, braille, body language, and more. A student named Miss Oy and her teacher from the Northern School for the Blind (NSB), both competent sign language users, assisted in mentoring other teachers. Meanwhile, Manee, a student from Lampang School for the Blind who is deafblind with complex communication needs, illustrated exemplary improvement in both her communication and literacy skills as a result of this camp. For example, one of Manee's learning objectives was to use signs to

make requests. Throughout the camp, teachers observed Manee requesting items, such as scissors, for activities at beading corner and on a variety of occasions. Manee and Oy became good friends and often used tactile sign language to communicate and play with each other.

Other visitors to the camp included a youth who is deafblind named Mr. Add, his teacher Tom, and a 65-year-old deafblind man named Puu. Upon the arrival at the camp, Oy was very happy to meet Puu and listened to his many life experiences, including his descriptions of the Songkran Water Festival. Tom, a teacher of students who are deafblind for 14 years, shared that he was very excited to see so many deafblind students spending time together. Tom said, "If I did not come see this camp today, I will feel sorry for the rest of my life." Tom's sentiment resonates well with many others who work with the deafblind community, as appropriate education and support for students who are deafblind is not yet a reality in Thailand. Lighthouse Family and ISAAC Thailand have created a partnership to promote AAC, including raising awareness and support from the Thai community. The activities at the Camp were filmed for the television program. A second television cooking program also filmed its show host making Pad Thai with the students. Both television programs, which promote positive images and highlight the incredible abilities of children and youth with deafblindness, have aired in Thailand.

Building upon the success of the camp, colleagues in Thailand have now established three different social media bodies, known as "Line" Groups, to exchange information. The first group, known as "Perkins Thai Gang", is composed of Perkins Educational Leadership Program (ELP) graduates and key colleagues in the leadership positions. The second and third groups consist of mentor teachers, and deafblind camp participants, respectively. These communities will provide ongoing opportunities for sharing and professional development in the future.

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## **International knowledge sharing: The Uganda Experience**

**By Nicoline Mostert and Trees van Nunen**

This article represents a progress report about a program 'Mainstreaming Deafblindness in Teacher Education in Uganda' previously reported in *Dbl Review* Edition 50 by Njuki, Locoro & Mostert (2013).

### **How this all started**

Following the dissemination of the needs assessment report (2011) developed to create a more sustainable support system for deafblind persons in Uganda, a Memorandum of Understanding (MoU) was signed between Kyambogo University

(Uganda), Sense International (Uganda) and Kentalis International Foundation (the international project office of the Royal Dutch Kentalis responsible for international knowledge exchange) with the aim of developing a new training program in the area of deafblindness at the University's Faculty of Special Needs and Rehabilitation. The objective of the cooperation was to improve services for children and young adults with deafblindness through developing a training program at Kyambogo University.

Through discussion with the cooperating parties, it was agreed that any lecturer in this program should have the following skills and knowledge: knowledge of interaction and tactile communication, Ugandan Sign Language, braille, orientation and mobility; knowledge of psychology and neuropsychology; counselling and guidance skills and especially an understanding how a person with deafblindness experiences their world.

During the last three months of 2011, two senior lecturers from Kyambogo University visited the Netherlands for an orientation visit and an exchange of expertise and ideas concerning the curriculum. This involved three months of practical training at Royal Dutch Kentalis. Part of their training was a four week theoretical course 'Introduction to communication with people with congenital deafblindness' at the University of Groningen. This course is part of the Masters degree program organized by the Kentalis chair, Professor Marleen Janssen. Part of the orientation program included visits with other deafblind programs in the Netherlands.

During the period May through August 2012, several training sessions were delivered in Uganda by experts from Kentalis to the future lecturers of the training program. Topics included: Orientation and Mobility, Communication and Interaction, Tactile Sign Language, Assessment and Diagnostics. In January 2013 an expert from Perkins International delivered training to the same group of future lecturers on the topic Transition.

Two other lecturers were selected to come to the Netherlands for a more in depth training on assessment and diagnostics. They were trained by the multidisciplinary Team Deafblind of the Diagnostic Centre of Kentalis. Their activities consisted of observing assessments and multidisciplinary meetings, studying assessment materials, visiting different deafblindness departments and literature study.

### **How it developed?**

These knowledge sharing activities resulted in the development of a Distance Learning Certificate Course comprising 14 modules. The content of the modules were published in 14 training booklets which were written and edited by the team of experts from Kyambogo University, Sense International and Kentalis International Foundation.

The illustrated booklets are attractive and very functional containing clearly formulated objectives and assignments. Several examples of the module topics include: Introduction to deafblindness and multi-sensory impairment (Module 1); Communicating with persons with deafblindness and multi-sensory impairment

(Module 3); Introduction to assessment (Module 5); Fieldwork practicum (Module 7); Guidance counselling (Module 10) and Transition (Module 13).

On January 2014 the pilot certificate course on Deafblindness and Multi-sensory impairment started for 10 teachers working with children with deafblindness. The first 7 modules were delivered during a two week course period at the unit for the Deafblind at Bwanda School for the Deaf in Masaka. Two experts from Kentalis were present during this pilot course to deliver hands on training to the lecturers. The feedback from the lectures, teachers and the Kentalis experts helped to fine tune the curriculum and the course content.

This all resulted in the curriculum being approved by the Kyambogo University Senate and Ugandan National Council of Higher Education in May 2014. The training program officially begins in August 2014.

### **Impressions of the project manager: Nicoline Mostert**

The preparation phase of this project started in 2010. At that time I was managing it all from my desk in Sint-Michielsgestel, the Netherlands. A stakeholder meeting in Kampala in November that year led to the final project proposal which was submitted to and approved and funded by Cordaid, a Dutch development aid organisation.

The project had its beginning on April 01, 2011. At that time I became a resident of Uganda, meaning I didn't need to manage the project from a distance anymore.

The strong point of this project is the tripartite partnership. This has resulted in a constant information flow between academic and practical experts from the Netherlands, academic lecturers from Kyambogo University and grassroots level experts from Sense International Uganda.

After receiving the theoretical information from the International experts, the trained lecturers were then given the opportunity, through the partnership of Sense International Uganda, to gain the practical understanding of both the urban and rural settings of the children with deafblindness and their families. This application of theory to practise made the knowledge transfer very effective.

The involvement of persons with deafblindness persons themselves, through the National Association of the DeafBlind in Uganda (NADBU), was very crucial when it came to making decisions in the process of developing the curriculum.

As a project manager on location I had easy access to the local networks around deafblindness and related areas in Uganda. As a result I was able to do continuous monitoring of the project activities and to adapt the project activities when needed. It also made it possible for me to give support to the Dutch experts when they came to Uganda to do the training. It then made it easier for me to ensure that the knowledge the lecturers received could be more easily applied after their training.

For the development of the training booklets it was crucial to translate the academic information into accessible language and to make it all culturally appropriate.

Therefore we approached Mango Tree Educational enterprises, a Ugandan company that is specialised in developing innovative tools for grassroots education in Uganda.

After 3 years of intense involvement of this project I am extremely proud that there is an approved certificate training program for deafblindness with high quality training resources available for all students.

### **Impressions of a trainer: Trees van Nunen**

As a member of the Kentalis Diagnostic Team Deafblind, I was initially involved in delivering training to the two lecturers from Kyambogo University in 2011. The next year (2012) I was approached to also participate in this project in Uganda to share my knowledge specifically in the field of assessment and diagnostics which resulted in my first visit to Uganda in August later that year.

During that one week training I worked together with the future lecturers of the Ugandan training program. The training covered such topics as: Working in a multidisciplinary team, carrying out observations and assessments, Challenging behaviour, Psychopathology and various syndromes. I was convinced that this training could only be successful if I was able to have a good collaboration with the lecturers in training. Right from the start I knew that this would become a memorable week because of the trainees' initial participatory attitude, their appropriate questions and discussions. What we all had in common was our interest in the field of deafblindness!

The most important thing I learned during this initial training session was the challenge the lecturers were all facing: making the knowledge that they gained from me, applicable for their situation in Uganda. After their training, two of the lecturers came to the Diagnostic Team Deafblind of Kentalis to learn more in depth about assessment and diagnostics under my supervision. This knowledge helped them in writing the training modules.

My second visit to Uganda was in January 2014 during the pilot certificate course. The first set of module booklets was now ready and my role was to train the trainer on – the - job. The 10 students in this course were all teachers working in schools for the deaf across the country that had attached programs for the deafblind.

During my visit I attended presentations of three modules, one (Introduction to Assessment) of which I delivered myself just a few months earlier. It amazed me to see how much knowledge these teachers had already. The lecturer of Kyambogo University had done a wonderful job; his lectures were very interactive and the students had the opportunity to practice their interview skills with a mother and grandmother of a child with deafblindness.

The last activity of the training was to search for assessment materials in the field of deafblindness. The students were able to find a variety of materials that can be used for assessments like stones in a plastic bottle, stones with various colours and textures and good smelling flowers.

During the rest of the week I attended the presentation of two other modules, Introduction to Uganda Sign Language and Fieldwork practicum. Since I was able to participate and get actively involved in the presentation, I felt that I was not only a trainer but was one of the students. Both the lecturers and the students were a source of inspiration for me especially because of the way they are handling the

challenges they are facing in the field of deafblindness in Uganda. I'm so very grateful that I had this experience.

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## **Developing evidence-based methods for improving high quality interpersonal communication with people who are congenitally deafblind**

**Marga Martens and Marleen Janssen**

### **Introduction**

Since 2008, research aimed at developing and studying the effectiveness of new interaction and communicating methods focused on individuals with congenital and early acquired deafblindness has been undertaken at the University of Groningen in the Netherlands through the leadership of Professor Marleen Janssen. Through the collaboration with Royal Dutch Kentalis, Bartiméus and Royal Visio in the Netherlands, studies have been performed in the real-life settings of children and adults with congenital deafblindness. This collaboration has provided an effective way of transferring expertise to the staff at these facilities, so that the people who are congenitally deafblind can benefit. As a result, questions from practice can be investigated and the outcomes of these studies on evidence-based implementation can be shared immediately.

The study presented here is one of four University of Groningen doctoral studies in progress that builds on the harmonious interaction study by Janssen, Riksen-Walraven & Van Dijk (2003a) which focuses on fostering high-quality interpersonal communication. The studies are also inspired by the Communication and Congenital Deafblindness series of booklets produced by the Dbl Communication Network (Janssen & Rødbroe, 2007; Rødbroe & Janssen, 2006; Souriau, Rødbroe & Janssen, 2008; 2009). The other three studies, which will be published in the near future, focus specifically on meaning-making (Saskia Damen), assessment of interaction and communication (Erika Boers) and bodily emotional traces (Kitty Bloeming).

In this article, the Intervention Model of Affective Involvement is briefly presented by Marga Martens.

### **Fostering affective involvement between people who are congenitally deafblind and their communication partners**

Affective involvement, or the mutual sharing of emotions, helps to maintain consistent orientation to the social environment, and to elicit and maintain positive emotions and limit negative emotions (Feldman, 2003). Affective involvement between people generally evolves naturally during their daily interactions. Mutual emotional exchanges are vital because they enhance social awareness and emotion regulation, which people need in order to communicate with others and develop. Sadly, affective involvement, which is so important for personal development and well-being, rarely occurs between people who are congenitally deafblind and their communication partners. The inability to engage in shared attention through eye contact and speech hinders them from sharing dynamic emotional exchanges (Hart, 2010; Janssen & Rødbroe, 2007). Due to the constraints they face in attaining affective interaction and communication, people who are congenitally deafblind are vulnerable to experiencing negative emotions and tensions. They have a high risk of experiencing stress and of failing to develop skills to cope with complex circumstances and negative emotions. It is therefore hardly surprising that Dammeyer (2011) found a high prevalence of self-injurious, aggressive, and withdrawn behavior among people with congenital deafblindness. Practitioners have asked for more practical guidelines for fostering affective involvement and reducing negative emotions in people with congenital deafblindness.

Previous studies have shown that despite the difficulties in sharing emotions, it is possible to train communication partners to increase affective involvement during their interaction with persons with congenital deafblindness (Chen, Klein & Haney, 2007; Janssen, Riksen-Walraven & Van Dijk, 2003b). Although it is the communication partners' responsibility to establish optimal conditions for promoting affective involvement, no studies have yet investigated whether affective involvement can be fostered during communication. Fostering affective involvement during communication may be even more complex and challenging for communication partners because it is difficult to focus on the content of expressions and exchange meaning while simultaneously preserving the flow of interaction and emotional exchanges.

### **The intervention model of affective involvement**

The aim of this PhD study was to provide theory and evidence-based guidelines for practice on how to foster affective involvement during interaction and communication between people with congenital deafblindness and their hearing and seeing communication partners. A two-phased Intervention Model for fostering Affective Involvement (IMAI) was developed for this purpose (see Figure 1; Martens, Janssen, Ruijsenaars & Riksen-Walraven, 2014a).

The IMAI builds on the Diagnostic Intervention Model developed by Janssen et al. (2003a), which has proven to be effective in fostering harmonious interactions with children who are congenitally deafblind. The intervention principles of the IMAI are intended to improve the communication partner's competence in a) recognizing individual affective behaviors, b) attuning to interactive behaviors, c) sharing meaning, d) sharing emotions during interaction and communication, and e) adapting the context.

Communication partners are trained during two subsequent phases in a seven-step intervention protocol that involves coaching with video analysis and video feedback. In Phase I, the communication partners are trained to foster affective involvement during interaction. During this phase, the communication partners are trained based on four core categories of interactive behavior (Martens, et al., 2014a):

1. Attention, defined as focusing on the interaction partner, the content of the interaction, and the persons and objects within the interaction context.
2. Initiatives, defined as starting an interaction or raising a new idea or an issue as part of a reaction.
3. Regulating intensity, defined as waiting while the client is adapting the intensity or pace of the interaction and is processing new information.
4. Affective involvement, defined as recognizing positive and negative emotions and sharing these emotions in a positive way that is perceivable for the client.

In Phase II, the communication partners are trained to foster affective involvement during communication. During this phase, the communication partners are trained based on three core categories of behavior (Martens et al., 2014a):

1. Shared experiences, defined as elaborating on events and introducing new events so that the client becomes motivated, feels secure, and knows what is going to happen.
2. Shared meaning, defined as interpreting and affirming the client's expressions of communication and using different turns to negotiate the correct meaning of those expressions.
3. Affective involvement, defined as recognizing positive and negative emotions and sharing these emotions in a positive way that is perceivable for the client.

### **Underlying theory**

The IMAI is based on theories about communication and early development such as those of Trevarthen & Aitken (2001), who stressed that emotions are vital in developing communication, and Stern (1985), who emphasized the key role of affect

attunement by the parent during their interaction with the infant. In describing affect attunement, Stern explains how infants feel understood when the parent responds correspondingly with the infant's overt behavior in such a way that the infant experiences that the parent's response is related to its own original feeling. Increasing evidence on affective attunement across different age groups has shown that mimicking emotions through the use of well-attuned facial, vocal, postural, and tactile feedback also fosters positive emotions and well-being in older children and adults with congenital deafblindness (Diamond & Aspinwall, 2003; for studies on older persons in nursing homes, see, for example, Custers, Kuin, Riksen-Walraven, & Westerhof, 2011, and Magai, Cohen, & Gomberg, 2002).

### **Applying IMAI**

The applicability and effectiveness of the IMAI was evaluated in three studies involving nine single-subject case studies (Martens, Janssen, Ruijsenaars, Huisman & Riksen-Walraven, 2014b; 2014c; in press). Seven trained coaches applied the IMAI to nine persons with congenital deafblindness and their 34 hearing and seeing communication partners. The case studies were applied to different communication partners (teachers, teacher assistants, caregivers, caregiver assistants) in three different settings (school, group home and daytime activities center) in five different organizations in the Netherlands.

The following research questions were formulated: (1) Do interventions based on our intervention model increase affective involvement between persons who are congenitally deafblind and their communication partners, and increase positive emotions and decrease negative emotions in persons who are congenitally deafblind? (2) Are these interventions effective during both interaction and communication? (3) Are they effective for different communication partners and in different settings, interactional situations, and organizations?

The outcomes were remarkable. There was very little affective involvement between the persons with congenital deafblindness and their hearing and seeing communication partners during baseline (i.e., before intervention started), but this increased in eight of the nine cases as soon as the intervention began. Positive emotions increased and negative emotions decreased for all nine participants with congenital deafblindness at the start of the intervention. In six of the cases, measurements were taken after 2, 4 and 6 months to examine whether affective involvement was maintained during follow-up. It was observed that affective involvement decreased during follow-up for all but one participant (however, it remained above baseline level in most cases). This suggests that coaching communication partners to foster affective involvement needs to be continued and should be a standard component in long-term staff development programs.

Future studies are needed to indicate whether the IMAI is applicable to others with congenital deafblindness, because the small number of participants limits generalization of the findings (Barlow, Nock, & Hersen, 2009).

## Conclusion

The study on fostering affective involvement shows that affective involvement supports people who are congenitally deafblind in reducing stressful experiences and in coping with stressors. Affective involvement also enables people with congenital deafblindness and their communication partners to experience more mutual contact and enjoyment in their relationship. We recommend that communication partners be regularly coached to foster affective involvement. If the guidelines that result from this study and the other University of Groningen doctoral studies are implemented properly, people with deafblindness will be given more possibilities to express and share their thoughts and emotions towards others. We hope to inspire our colleagues in the field to read more about fostering affective involvement and the subjects of the other studies, in the hope that this will help create more possibilities for people with deafblindness to develop further with regard to interaction, communication and language.

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## Figure 1. Intervention model for affective involvement during interaction and communication

### Aim

To foster affective involvement during interaction and communication between persons with CDB and their communication partners

### Intervention Principles

To improve the communication partner's competence in

- a) recognizing individual affective behaviors
- b) attuning to interactive behaviors
- c) sharing meaning
- d) sharing emotions during interaction and communication
- e) adapting the context

### Intervention Protocol

1. Determining the question
2. Clarifying the question

Phase I: Interaction

3. Interaction analysis

Aims of the intervention in terms of four core categories of behavior:

- a. attention
  - b. initiatives
  - c. regulating intensity
  - d. affective involvement
4. Implementing intervention focusing on interaction

Phase II: Communication

5. Communication analysis

Aims of the intervention in terms of three core categories of behavior:

- a. shared experiences
  - b. shared meaning
  - c. affective involvement
6. Implementing intervention focusing on communication
  7. Evaluation

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## **A new information portal for people with vision and hearing loss (in old age) in Switzerland**

Sensus60plus.ch has been launched in response to the large numbers of elderly deafblind people in Switzerland

Elisabeth K. had always enjoyed an active life. She loved dancing, and music was her passion. Over the years, however, she noticed that her sight and hearing were deteriorating. Now she can barely see anything at all, and only reacts if her hearing aid is switched on. Elisabeth K. has become hearing and visually impaired. She is over 80 years old.

### **Deafblindness in the elderly: an underestimated phenomenon**

The study “The living circumstances of deafblind people at different stages of their lives in Switzerland” was published jointly in February 2011 by The Swiss National Association of and for the Blind (SNAB) and The University of Applied Sciences of Special Needs Education in Zurich (Interkantonale Hochschule für Heilpädagogik). Two fundamental findings of this first broadbased investigation were that previous estimates of the extent of deafblindness in Switzerland are far too low (the study speaks of up to 200,000 people being affected), and that increased life expectancy has led to a sharp rise in the number of elderly people, in particular, suffering from deafblindness.

The research results are complemented by the following real-life observations from the SNAB’s advice centres: Deafblindness, or deteriorating vision and hearing, amongst the elderly is an underestimated phenomenon, which neither the services for the hearing and visually impaired, nor the various facilities and institutions for the elderly in Switzerland are well equipped to cope with. A large proportion of the people affected are often neither recognised as “deafblind” nor regard themselves as such, since they perceive any decline in their vision and hearing – if indeed they notice it at all – as part and parcel of getting old, or (mis)understand it as the beginnings of dementia. People who (only) experience problems with their hearing and vision in old age, and their relatives, therefore tend not to consult advice centres and other services that have been set up specifically for “the disabled”.

A third factor is the current way in which the SNAB’s advice centres for deafblind people are organised. Across Switzerland there are seven advice centres, providing advice, support and a programme of social events to around 350 deafblind people. All the services (practical advice, rehabilitation, entertainment, skills training) are working at full capacity. Expanding the number of clients to 10,000 or more is out of the question; the SNAB could not cope with such numbers. Besides, the centres position themselves as advice centres for the disabled, which makes it unlikely that people who do not regard themselves as “disabled” in the traditional sense would use them.

### **What are the challenges?**

The SNAB is considering the following:

- How can the public be made more aware of the issue of age-related / acquired deafblindness, and the enormous problems caused by visual and hearing impairment in old age?
- How can hearing and visually impaired persons be reached initially, if they do not regard or describe themselves as disabled?
- How can help and support be offered to those affected, as well as to their family and the medical and care staff around them?

### **Relatives need support too!**

Elisabeth K. still lives at home. She is fortunate that her daughter was quick to identify her needs. The daughter has adapted the environment to the needs of her mother, so that the old lady can still live as independently as possible. However, the daughter is angry that hospitals, on the other hand, take such little account of the needs of elderly deafblind people: "If a glass of water is just put down in front of her she will still be thirsty, because she simply cannot see it any more," she says. She believes that much greater awareness of the issue is needed: Trip hazards need to be removed, rooms need to have better lighting, and utensils such as cutlery and crockery need to be as high-contrast as possible.

After evaluating the study, it was clear to the SNAB that the issue of deafblindness in old age needed a campaign which would last several years. The result is a campaign which focuses on new target groups – above all, people who have only experienced visual and hearing impairment in old age and do not regard themselves as "disabled", together with their families and care institutions. The campaign's working title is "Impaired Vision and Hearing in Old Age", and its objectives are to provide information and promote changes in behaviour, as well as to promote practical measures for adapting people's environments and making their everyday lives easier.

### **Harnessing the web to reach more people**

As a first step, the trilingual website ([sensus60plus.ch](http://sensus60plus.ch)) was set up at the beginning of 2014. The website takes the following questions as its starting point:

- I can't see or hear very well – is it just because I'm getting old?
- My mother / father can't see or hear very well any more – is she / he suffering from dementia?
- Our patients' vision and hearing is deteriorating – what can we do?

The portal's target audience is elderly people with impaired vision and hearing, their relatives, and the professionals who come into contact with them in hospitals, nursing homes or when caring for them in their own homes. There are lists of questions, which help to ascertain whether vision and hearing impairments exist. The site provides tips and details of simple measures that can be taken to better exploit vision and hearing potential, and compensate for difficulties. It gives details of the people to contact for direct information, and has links to services provided by

other organisations for the elderly. The objective is always to improve the quality of life of the people affected.

The website [sensus60 plus.ch](http://sensus60.plus.ch) is, and can only be, a first step towards achieving that goal, but it is certainly not the last. Thanks to demographic change, which will see a steady increase in the number of elderly people in Switzerland in the coming years, there remains a great deal more for the SNAB and its partner organisations to do.

For more information contact: Ann-Katrin Gässlein and Tina Aeschbach  
The Swiss National Association of and for the Blind (SNAB) ([www.szb.ch](http://www.szb.ch))  
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## **ONCE Tactile Communicator (CTO)**

### **An app to improve deafblind people's communication**

CTO is an application for Apple and Android mobile devices. It has been developed by ONCE through CIDAT (ONCE's Center of Research and Development for Tiflotechnic Implementation) in collaboration with UTS (ONCE's Deafblind Department).

CTO enables deafblind people to communicate face to face with seeing-hearing people (who don't know the communication systems of deafblind people ie manual alphabet, sign language, etc) by exchanging written messages through their own smartphone or tablet.

This application is aimed at deafblind users without any functional hearing, who cannot therefore receive spoken messages through their auditory system.

Depending on the user's residual vision, CTO can be used in two different ways. If the users don't have any functional vision, they may use this application on their mobile phone through a Braille device, the same that they normally use to have access to the rest of the applications of their mobile phone. On the other hand, deafblind people who still have residual functional sight will have access to this application through the phone screen itself.

In the first situation the Deafblind user (those without functional vision) writes and reads the messages on his braille device (which includes the braille keyboard and the braille line) connected by Bluetooth to the mobile phone. The partner can answer in two different ways: writing the message with the virtual keyboard that appears on the tactile screen of their phone or dictating the message to the phone; it will then be transformed into a written text, thanks to the telephone voice recognition system.

In the second situation the deafblind user (with some functional sight) may write, depending on his visual acuity:

- With his own finger on the screen through a strokes code based on the capital letters of the regular alphabet.

- Or through the virtual keyboard of the mobile device itself.

As in the case of the deafblind users that are functionally blind, the partner can answer in two different ways: writing the message or dictating it. The deafblind user will be able to read the message, by adapting the visual accessibility characteristics of the text (colour, size...) to their own needs.

Finally, if the deafblind user has understandable speech, it means that he can transmit his messages orally, so he will only use the CTO to have access, either in Braille or in regular characters through the screen, to the information expressed by the partner.

The application also has the following options:

- A self-learning section to improve the recognition of key strokes.
- The user has the possibility to customize the size, contrast, colour, different kinds of notices, etc.
- Creating messages and saving them to use later in specific communication situations as well as using other predefined messages that are kept in different subject folders.

It enables a great integration with other functionalities and existing applications on the mobile device, such as the use of the clipboard, sending SMS or e-mail, etc.

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For further information:

<http://cidat.once.es/home.cfm?id=1533&nivel=2>

Download link for CTO for IOS:

<https://itunes.apple.com/es/app/comunicador-tactil-once/id796383236?mt=8>

Download link for CTO for Android:

<https://play.google.com/store/apps/details?id=es.once.comtactil&hl=es>

## **Communication and Congenital Deafblindness Articles**

**Four booklets on Communication and Congenital Deafblindness, developed by the Dbl Communication Network, are available now in Spanish.**

The Spanish National Organization of the Blind (ONCE) recently published, in Spanish, the four booklets produced several years ago by the Dbl Communication Network. The translation was done by ONCE's Deafblind Department professionals according to the legal conditions agreed to with the Dbl Communication Network. The four booklets are: Congenital Deafblindness and the Core Principles of Intervention; Contact and Social Interaction; Meaning Making, and Transition to the Cultural Language. These booklets present the theoretical framework developed by the Dbl Communication Network over a ten year period. The material provides

important insight into intervention with people with congenital deafblindness. The booklets are accompanied by a DVD with video recorded case studies. This material was prepared by the Dbl Communication Network to support the personal network of people that surrounds each individual with deafblindness. This network includes the family and the interdisciplinary team of professionals who work with them. The aim of this work of the Dbl Communication Network was to facilitate, based on the knowledge of human communication development, a better understanding of how to work with congenital deafblind people to develop and enhance their communication.

Each booklet has an accompanying DVD to illustrate the main concepts presented in the 4 booklets. Each DVD presents good examples of interactions between deafblind children and their communication partners .

For further information, Email: [asdocdg.publica@once.es](mailto:asdocdg.publica@once.es)

## **An Exceptional Fellow: A Father's Story**

by Svein Olav Kolset

### **An Exceptional Fellow:**

A Father's Story is now available as an E-book through the website:  
[Anexceptionalfellow.com](http://Anexceptionalfellow.com)

This book is the unsentimental and powerful story of a deafblind child, now 39 years old, with CHARGE Syndrome. Against all odds Torgeir has fought for and achieved a life of dignity. He experiences mastery and meaning on his own terms. How is that possible with serious sensory debilitation and other physical impairments? The website ([Anexceptionalfellow.com](http://Anexceptionalfellow.com)) provides options for purchasing the book, inquiring more about the author and his family as well as seeking answers to additional questions of the author.

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## **CHARGE Network**

### **Andrea Wanka reports:**

The annual meeting of the 'Nordic Network for CHARGE Syndrome' met in Lund, Sweden, May 13-14, 2014. The topic for discussion was: "What can we do to better support persons with CHARGE Syndrome in social relations. Representatives from each country presented case studies about this important issue. The next meeting is scheduled for May 5- May 6, 2015, either in Denmark or Iceland.

The 8th international German CHARGE conference takes place July 3rd till July 6th in Oberwesel, Germany, hosted by the German CHARGE group. Speakers will include Dr. David Brown (USA), Prof. Dr. Tim Hartshorne (USA), Gail Deuce (UK), Dr. Kim Blake (Canada) and Prof. Dr. Conny van Ravenswaj (Netherlands). More information is available at: <http://www.charge-syndrom.de/index.php/termine-treffen/>  
A German book on youths and adults with CHARGE Syndrome with articles from people with CHARGE, their families, friends, colleagues and professionals will be available soon (in the German language).

For more information, please contact Andrea Wanka:  
[Andrea-Wanka@dbicharge.org](mailto:Andrea-Wanka@dbicharge.org)

## **European Deafblind Network**

### **Ricard López reports:**

It has been a long time since the last time we wrote a report for the Dbl review. However, we have done a lot of interesting things that we would like to share with you and we are going to present them all below:

Taking advantage of the celebration of the 8th Dbl European Conference, which took place in Lille, France on 24th August, EDbN organized two different events: a seminar about the project European Deafblind Indicators, funded by the European Commission, and also the annual EDbN assembly, which was very well attended. Many partners at the European Deafblind Indicators project gathered to have a very fruitful working day. The project worked very well thanks to the involvement and expertise of the professionals of the member organizations. (See the specific article about the project).

The annual EDbN assembly dealt with some important issues that we would like to comment:

Firstly, we emphasized the fact that the EDbN president Ricard López had been elected as a board member of European Disability Forum (EDF) which allowed us

to increase our influence and visibility. We are very proud to represent deafblindness in this important forum.

Thereafter, we appointed Peter Fasung from Slovakia and Eda Kedves from Hungary as EDbN board members.

Finally, we posed three important questions to the European Parliament which it will address to the European commission, as follows:

- “I can connect”: this is a proposal to provide accessibility equipment to low-income individuals who are deafblind.
- The current lack of statistics. Therefore, we want Eurostat or FRA (European Union Agencies for Fundamental Rights) to develop accurate statistics data on deafblindness.
- The urgent need of a census. The idea is to achieve a policy action of the EU over its member states.

The members of the European Deafblind Indicators project also took advantage of this chance to present the most relevant elements within each domain, divided into three Working Groups and gathered in a Network Session of the Dbl Conference. The first Working Group took place the 26th August, and the information was addressed to all the CEOs and information officers. The aim of this event was to get to know better EDbN, how it works for deafblindness and how to use these progresses in the situation of each country.

We also wanted to discuss about an important organization and platform such as EDF and the European Platform of Deafness, Hard of Hearing and Deafblindness, and how important is the role they play in representing all the people with hearing impairments, not only with deafblindness. We all agreed in our priority areas of interest: accessibility, structural funds, complex needs, institutionalization, The United Nations Convention on the Rights of Persons with Disabilities, statistical reporting, lobbying and employment.

Finally, we ended up informing them about the European Deafblind Indicators project and also the project “I can connect”, two initiatives in which we have been working for a long time and we would like everyone to get involved in.

The other two Working Group participants were similarly informed about EDbN, its aims and future plans; encouraging participants to join us.

The Annual General Assembly was held in Barcelona on the 20th June. During this same time in Barcelona, the European Conference on Deafblindness took place at the Caixa Forum auditorium. During that conference our project, the European Deafblind Indicators Project, for which we have been working for more than two years, was presented. You will find more information about this project on the deafblind indicators project website ([www.deafblindindicators.eu](http://www.deafblindindicators.eu)).

For further information, do not hesitate to visit our website [www.EDbN.org](http://www.EDbN.org) or follow us on Twitter @Deafblindness. Keep in contact with us so you do not miss the exciting news that are going to take place in Europe!

Ricard López,  
EDbN President

## **Outdoor Network**

### **Joe Gibson reports:**

This has been an exciting period for the Outdoor Network. The number of members has grown after presentations in both Brazil (V International Forum on Deafblindness and Multiple Sensory Disabilities, November 2013) and Canada (7th Spirit of Interveners Symposium, March 2014) about the use of the outdoors and the work of the network meaning there are now over 70 members.

We have also sent out our first "newsletter" (see below), which will hopefully become a regular feature detailing what the members have been doing and publicising events.

Soon we will have some dedicated web space on the Dbl website ([www.deafblindinternational.org](http://www.deafblindinternational.org)) to share news, ideas and to advertise events. Until then I will try and send out a newsletter to keep everyone updated. If you have any stories about your work in the outdoors you wish to share, or links to research or video's please let me know and I will add them to the next newsletter!

### **Dbl European Conference Lille, France 2013**

At the Dbl conference held in Lille in France in 2013 the Outdoor Network presented during the network day for the first time. We showed a video from the 2012 Outdoor Network week (<https://www.youtube.com/watch?v=IJKakhh3SeM> ). We also discussed the future direction of the network.

### **Outdoor network week 2013**

In September Outdoor Network week was held in Sømådalen in Norway. Nine participants with deafblindness from three different countries and sixteen support workers explored and enjoyed the Norwegian mountains together. The week was spent outdoor hiking in the mountains, rowing in the windy weather, fishing in the lake, picking potatoes in the field, cooking at the fireplace and falling asleep on a reindeer skin next to the fire.

See the movie from the Sømådalen week:

<http://www.youtube.com/watch?v=grXvK8HPVZo&list=UUj7RyOERI4cTXnCa08fle6A&feature=c4-overview>. This is a film from Christine Hanberg.

### **The outdoor network week September 2014**

In 2014 the next Outdoor Network week will be held in Denmark during week 38 (15th-19th September 2014). The week is open for people who are deafblind and

workers who are interested in the outdoors. For more information please contact Peter Mathiasen (pema@rn.dk).

### **The outdoors as a part of everyday life**

Participating in the September outdoor weeks is one week of the year. The nature is outside your window everyday and there are many ways to enjoy and use the nature. Only your imagination is the limit. For some ideas see the <http://accessibleoutdoors.blogspot.co.uk> blog, aimed at teachers working in special schools. It offers ideas of ways of taking the classroom outside and using the natural environment to help in the learning process. If you have any ideas or techniques you would be willing to share on the blog please let me know!

[jgibson@sensescotland.org.uk](mailto:jgibson@sensescotland.org.uk)

## **Newsletter No. 1**

### **Welcome to the first newsletter from the Dbl Outdoor Network!**

The Outdoor Network is for all people who enjoy or use the outdoor environment. It is open to people whose deafblindness is either acquired or congenital as well as to support staff and families. We currently have one annual event, the Outdoor Network Week where people who are deafblind and their support workers meet to explore the nature, share experiences and get inspired.

## **Social-Haptic Communication Network**

### **Riitta and Russ report:**

The Social-Haptic Network has been collaborating with the Signo organization<sup>1</sup> in Norway. After a one-day professional meeting and teaching day, Signo organised a six-day social-haptic communication course in Andebu. The tailor made programme for the professionals working at Signo was developed according to three levels: Basic, Intermediate and Advanced. These different levels included basic concepts on social-haptics and haptemes (grammar), which allow the opportunity to exchange ideas and practical tips on how to apply haptices (touch messages onto the body) with different client groups. During the learning process the delegates were able to discuss through skype or email with Riitta and Russ on specific related issues on how to apply haptices.

Co-operation with Royal Association for the Deaf in the UK and Royal Dutch Kentalis in The Netherlands gave the opportunity for the professionals, interpreters, deafblind people and family members to work together in a one day workshop to discuss and share experiences on how social-haptic communication can be used in everyday life.

The Finnish National Board of Education has accepted the Instructor of Haptics skills level course as a part of the Special Vocational Qualification instructor's curriculum of Visual Impairment skills at Vocational College (Keskuspuisto) in Finland. Other special instructor areas include educational disciplines from low vision and mobility training, IT and Braille for the blind. This pilot research project course lasted for a year and set the standards for the process to learn and use haptics with blind and deafblind people.

KELA, the Social insurance institution in Finland (Governmental Social Services Department), has recognised Haptics as an official communication system for deafblind, visually and hearing impaired people. Trainee students and qualified Sign Language Interpreters who wish to specialise working with deafblind people, now have the opportunity to do extra studies of 3 credit points (78 hours work) courses on social-haptics.

Research and development projects with professionals from the Universities of Turku and Helsinki are continuing in the areas of Musical Haptics.

The second Social-Haptic Communication Network meeting took place during the International Accessibility and Multimodality in Communication symposium at University of Turku in 2013. More information and subject related abstracts can be found on the website <http://tucs.fi/conferences/acmuc2013/>

We would like to announce that we were married in November 2013 which took place at Signo's new Multi-Sensory Church<sup>2</sup> in Andebu, Norway. Some of you may be aware that we first met during the 10th IAEDB World Conference, in Orebro, Sweden in 1991 where we were both giving our own workshops on Usher awareness. Check out <http://tb.no/nyheter/gode-vibrasjoner-for-de-nygifte-1.8152492> to see some of our wedding photos. Our special thanks to Signo for their support.

For further information about the Social-Haptic Communication Network, contact: Riitta Lahtinen ([riitta.lahtinen@kolumbus.fi](mailto:riitta.lahtinen@kolumbus.fi)) or Russ Palmer ([rpalmer2@tiscali.co.uk](mailto:rpalmer2@tiscali.co.uk)). [www.russpalmer.com](http://www.russpalmer.com)

## **Usher Network**

### **Emma Boswell reports:**

Ten months have passed so quickly since the 8th Dbl conference in Lille, the croissants and coffee creams almost seem like a thing of the past!

It was an amazing experience for me to meet my counterparts from all over the world, as well as learn about the Usher community far and wide.

I am proud to say that alongside the many plenaries and workshops, the newly reformed Usher Network Group hit the ground running and forged what has proved to be a strong and very enthusiastic committee. Even with technological and time zone barriers, we have carried on with the same zeal as our first meeting in Lille. Thanks to the advanced technology of Skype, we have arranged meetings around the world time zones, with Constance Miles in the USA waking very early in the morning, and Karen Wickham staying up very late in Australia. We have shared morning cups of coffee and the odd nightcap, with me enjoying afternoon tea, all in the spirit of ensuring the UNG is a success! Not to mention Nadja Högner (Germany) and Marion Felder (Germany) managing to find time in middle of their lectures at University to join us. Tatiana Bagdassaryan has found Skype connection difficult due to a lack of support in her native Russia - this is something that we are still working on and hoping to resolve in the near future. One thing that the erratic hours and technology hasn't dampened is our sense of humour! We are a lively and proactive group.

However, with only five months left before our Usher Network pre-conference we still have much to do. It was our initial aim to provide a space for professionals, families and people with Usher to come together, learn from one another as well as support each other and we are delighted with our programme.

We will be holding the pre-conference in Northern Ireland on 3rd and 4th November (please see the advert in this magazine for more details). Together we have found some fantastic speakers, not to mention some surprises to be announced nearer the date. So if you have an interest in Usher, work alongside, or within the Usher community, please come and join us at the pre-conference

We will also be developing new sections on the web about the Usher Network in the near future, so watch this space.

To register on to the pre-conference, please contact us via [emma.boswell@sense.org.uk](mailto:emma.boswell@sense.org.uk)

## **DbI Youth Network (DBIYN)**

### **Simon Allison reports:**

We are very pleased to report that membership continues to grow steadily since our formation in January 2014. We have 155 young deafblind members and 55 associate members from 5 different continents.

Our team of 15 country representatives are in place world wide to share information on the network with their colleagues. Countries represented are Malawi, France,

USA, Norway, United Kingdom, Canada, Australia, Romania, New Zealand, Netherlands, Iceland, Finland, Brazil, Denmark and Sweden. The country representatives are supported by the network coordinator.

Through our social media pages we have provided an opportunity for young deafblind members to form links with each other. Our Country representatives have been able to assist with communication support to nurture and develop these friendships.

DbIYN has asked its members to submit 'success stories' that give an insight into how deafblind youth overcome challenges they face in their lives. There has been a fantastic response with the network inundated with a wide range of inspirational stories. Each story has been published on the network Facebook (<https://www.facebook.com/groups/dbiyouthnetwork>) group page. It is expected that the completed collection of stories will be available in a range of formats by the summer of 2014.

The network published its first newsletter (Summer 2014) which updated members on International activities and events involving deafblind youth. The newsletter includes updates on youth services from the country representatives and profiles of network members. The network welcomes contributions for the next letter to be submitted to the Network coordinator by August 31st 2014.

Simon Allison  
simon.allison@sense.org.uk

## **Rubella Network**

### **Joff McGill reports:**

Much work is taking place around the world on rubella. In the Netherlands two organisations, Batimeus and Kentalis, are undertaking a longitudinal study about the impact of CRS in adults, comparing individuals' health and wellbeing now and 10 years ago.

In Canada, work is well underway on an update study looking at the ongoing health problems for people with CRS. The Canadian Deafblind Association produced a survey fifteen years ago that looked at the Late Manifestations of Congenital Rubella Syndrome.

Sense International are working hard with various politicians, public health bodies, and researchers in Tanzania, Kenya, Uganda and India to build the evidence needed to develop immunisation programmes to prevent rubella and CRS.

At the 9th Australia National Conference in Sydney, organised by Foresight Australia, participants were invited to tell their story, to share their collective knowledge, experience and insights of rubella. Watch this space for the exciting work that may emerge.

Initial thinking and planning is underway to ensure the Network has a full programme at the Dbl World Conference, May 2015 and that the programme reflects content on

prevention of rubella and CRS, the ongoing health problems experienced by people with CRS and the support and services needed for the 100,000 babies born with CRS around the world every year.

So, exciting times for the Network with much to share and learn.

Joff McGill

(Joff.mcgill@sense.org.uk)

## **Congenital Rubella Syndrome – An Emerging Multi-Faceted Relationship**

**Susannah Barnett**

**Former Research Officer Sense**

**susannahmobilephone@gmail.com**

### **Introduction**

Sense has been undertaking a study into the long term impact of Congenital Rubella Syndrome (CRS) for a number of years. This paper deals particularly with the qualitative data resulting from the study.

Through the analysis of the qualitative comments it became apparent that what was being described did not match the expected picture relating to the commonly known 'late manifestations' of CRS, but rather what emerged was a very different picture describing a multi-faceted 'relationship' with CRS. This relationship not only affects the person with CRS and their relationship with the syndrome, but also the family and carers and whose lives were also affected through their connection with the person who has CRS and the decisions which resulted.

### **Methodology**

The comments were analysed using a Grounded Theory Methodology that seeks to develop an underlying theory from natural response data. Whilst the process involves both induction and deduction, induction is given priority. The meaning is discovered, developed and provisionally verified through systematic data collection and analysis of data pertaining to the phenomenon being explored. The method does not begin with a theory and use data to support it. Rather, the process begins with an area of study and what is relevant to that area is allowed to emerge (Strauss and Corbin 1990).

From the surveys and interviews the qualitative comments were extracted and put into a separate document. These were then coded. Coding is the act of attaching a conceptual label to a piece of data. Coding can be done in a number of ways, but always has the aim of finding or building concepts. (Urquhart, 2013)

Finally, categories and conceptual themes began to emerge, including the one which became known as the core variable – Living Relationships.

'Living relationships' was defined as the core variable for a number of reasons. Core variables in Grounded Theory commonly describe an adjective; it is the act of 'doing', or 'undertaking' an action which becomes the variable which links the categories and concepts. 'Relationship(s)' are the end result of two people/ points meeting in some way, not the act itself. Whilst 'creating', 'making' or 'forming' relationships would have fulfilled the criterion for a core variable; each of these options implies a will to make the relationship, even a positive will, both sides being active in the process. However in the case of Congenital Rubella Syndrome, the relationships which were formed as a result were not out of choice, but out of necessity. Equally the nature of the relationship was not always positive, and both partners did not have an 'equal' choice. Sometimes CRS itself had the greater part in the 'relationship', those the syndrome 'related to' could do nothing other than to follow where the syndrome (and all it entailed) took them. In other instances, as will be seen, other establishments had a greater part in the relationship. Therefore 'living relationships' was chosen, as this expressed a very real life altering process which people experienced, with a much wider net than just those affected themselves. 'Living relationships' also expressed a concept that is alive, i.e. is still evolving. People with CRS, their families/ carers, medics, educationalists and the 'state' are all still affected by this central phenomenon – that is Congenital Rubella Syndrome.

## **Results**

The full results can be seen on the Sense ([www.sense.org.uk](http://www.sense.org.uk)), along with other reports and papers resulting from the British CRS Study.

## **Conclusion**

The study makes a modest contribution to an area which has thus far been little researched within the U.K. There have been some studies into the Late Manifestations of Congenital Rubella Syndrome internationally (Gregg, 1941; O'Donnell, 1995; Munroe, 1999; Nicholas, 2000; Khandakar, 2004 and Dannemeyer, 2010).

However none of these were undertaken using a Grounded Theory Methodology. It was through the use of GTM, and the emergent nature of this method that it became apparent that whilst the central phenomenon remained the topic of Congenital Rubella Syndrome, the core variable was the concept of 'relationships' i.e. the data from both individuals with CRS and other parents/ carers of people with CRS concerned their relationship with 'CRS', both as a subjective experience but also as an objective phenomenon. This phenomenon has the ability to bring out in people actions of extreme courage and determination in standing up against the prevalent culture of the time. This was something that no one was prepared for – beyond the expectation of the birth of their son /daughter. They were led down a path they had never envisaged by CRS.

Yet equally the CRS epidemics prompted a reaction within the medical and educational institutions. They also had to deal with this new phenomenon and they 'coped' in different ways too.

What is clear throughout this study, and when reading the comments and narratives from the parents and carers of people with CRS, is the nature of the relationship they have with their children. Theirs is one of total love, and an incredible, enduring and ongoing strength they give to their children and use on behalf of their children. This love is shown through opposing the professional medical and educational establishment structure, and defending their views on what is 'best' for their child. It also entails opposing the prevalent culture of the time, not wanting their child institutionalized, not accepting labels of 'psychotic' and very simply never walking away. It is possible to assume, (or easier to assume) that these types of experiences were linked to British society of the 50's and 60's. The evidence shows that the actual experience of CRS may have changed but the challenges remain. Ignorance and marginalization are one of a range of issues that came from society, including a lack of tolerance, acceptance and help from people who should know better. At the very least, in the absence of knowledge, those people should certainly have tried to learn and do better.

Finding what was 'right' has never been easy (then or now). Rubella and CRS were new to these parents. They had no precedents. Yet they did feel their way along, and instinctively, in many different ways, a path was found for the child, the parents/carers and their families, at a self – sacrificing cost to themselves perhaps. The relationship with CRS objectively therefore became one of hardship, yet a great service to their child, born of a relationship of natural love, still occurred.

Sixty years since the birth of some of the first babies with CRS; the "rawness" of emotion evident in the parents'/ carers' testimony of their love, and the battles they fought hasn't changed. It is depicted not only in the written survey responses – the depth of information given and the time it must have taken to share and talk about their child, the revelation of their own feelings and the honesty in their writing – but also in the raw emotion, the public tears that were shed in some of the face to face interviews. Why? Because parents and carers are still giving and they still want to give what they can for their children, even where children have grown and now live in other settings apart from the family home. Parents are desperate to help in any way they can for the improvement in the quality of life of their child now – and in the future. They are still desperate to contribute what they can to the accumulation of information about CRS in the hope that in their own passing, any information and knowledge shared will help. Their world has been fashioned so completely by being part of the wider CRS family.

Then there are those individuals who have a relationship with their own CRS. They answered questions too and likewise had many questions to ask. Their world again has been fashioned by CRS. They want answers to their own condition that in some ways the study will not be able to give – beyond the statistics of who else has the same anomalies within the wider CRS spectrum.

For people with CRS themselves, their particular input has been the revelation of their feelings of being 'different' to other members of their family. They experience

the presence of others and the need to survive others' perceptions. Their self perception, perhaps one of marginalization or of inferiority – is also one of pride. Pride in who they are and in their lives, how they have organised their lives and in their achievements of milestones that often those around them thought would be unachievable. They should also accept pride in their own contribution to this study and the authentic record that has now been created. Time has moved on, sixty years have passed. CRS has touched the lives of many people in a whole myriad of relationships, on both an objective and subjective level. The antithesis of positive and negative, of awful neglect and overwhelming, all consuming love and support, a lack of understanding, a desire to be understood and a need for greater understanding by those who try their best to understand. Still there are questions, and still contentment is sought but not completely found. Somehow there is a realization that for now there has to be an acceptance that answers cannot yet be given.

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## **Developing a Checklist for assessing the social skills of Deafblind/MSI children in Tamil Nadu, India**

**Leela Agnes, D. Maikandan, V. Thiruvalluvan and Immanuel S. Prabakar**

### **Abstract:**

Deafblind and Multi -Sensory Impaired children face severe challenges in social skills development. Care givers need to know the present level of functioning of this group of children in order to develop Individualized Intervention Plans. Based on 12 factors contributing to social skills development and the impact of disabling conditions, the authors created a checklist. The authors plan to use this checklist to assess social skills of this group of children and relate the same to language skills.

### **Introduction:**

Deafblindness/MSI is a rare condition which can cause a number of severe difficulties, such as: problems in communication, having a distorted perception of the world, a deprivation of information necessary to anticipate the future events or the results of his/her actions, and challenges in establishing and maintaining interpersonal relationships. These problems have a direct impact on social cognition and attaining social skills appropriate to their age and need. Hence developing a checklist to assess the social skills of deafblind/MSI children is a priority. Such a checklist will assist parents, special educators, Community Based Rehabilitation (CBR) workers and other care givers to establish an in depth understanding of the present functioning of the child, so that goals can be established as part of an Individualized Intervention Plan based on the individual needs of the child.

### **Social Development:**

Through their growth, children come to understand the multifaceted social world around them, and eventually decide the quality and content of their social lives. Human beings enjoy being part of a social world and their emotional behavior to a greater extent is regulated by the social experiences gained in childhood. This is also called 'Social Cognition'; children think about and interpret experiences, not only based on their physical surrounding but through themselves and other people. Stages of Social Development are well documented in various publications, including (Prabakar and Agnes, 2013).

Deafblindness/MSI conditions creates number of challenges limiting the establishment of the following social skills (Hand Book on Deafblindness, Sense International India (undated).

- Inability of parents/teachers/peers to understand the communication modes of this group of children.
- Problems in acquiring basic life skills which can be interpreted by others as low cognitive functioning.
- Inability to interact with significant others in their lives.
- Problems in exploring the environment and establishing personal relationships.

### **Developing a tool to assess social Skills of Deafblind/MSI Children:**

In order to develop a tool to assess social skills of deafblind children, we need to consider these two factors: a) the underlying issues contributing to social skills development in children, and b) the impact and special needs of children with Deafblindness/MSI conditions.

The researchers preferred a checklist approach as a possible tool for assessing the social skills of deafblind/MSI children due to the following advantages (Wilson, Barbara A. (Undated):

- Time and labour efficient
- Comprehensive as it can cover many areas
- Represents a documentation of development
- Serves as an individualized documentation for the child
- Demonstrates a clear illustration of the developmental continuum
- Is a facility that can assist in knowing the needs of the child and developing goals for intervention.

The factors contributing to social skills of the child, which are considered in developing the checklist, relate to:

Self (of the child); Achievement motivation; Self-definition based on self-image; Feeling of helplessness; Understanding social situations; Social problem solving; Adequate/Appropriate social responses; Social behaviour; Peer relationships; Self-Management; Compliance skills and Language/communication.

### **Methodology:**

Since the Checklist to Assess Social Skills for Deafblind/MSI Children needs to address the two factors already mentioned, the researcher created a checklist based on established checklists for deaf children and autistic children (Winner, Undated a&b). The questions that are part of the checklist were field tested with the special educators who work with Deafblind/MSI children in Tamil Nadu. Based on the feedback from the special educators the checklist was finalized.

The Checklist was then applied with a group of 10 children who are deafblind/MSI as part of a pilot study. This pilot study was conducted as part of research work at Pullambadi Block of Trichy District<sup>5</sup>. Based on the results of the pilot study, appropriate changes were made to prepare the final Checklist.

The Checklist is organized according to a grid system. Along the vertical or 'y' axis (ordinate) are listed 43 questions organized according to the 12 factors areas contributing to social skills of the child (mentioned above). Each social skill factor is assigned a number of questions. See example below. The horizontal or 'x' axis (abscissa) represents the rating system (Always, Sometimes, Rarely, Never and Not applicable) for each of the 43 questions.

The full checklist can be downloaded from website of the Holy Cross Service Society ([www.hcsstrichy.com](http://www.hcsstrichy.com)).

### Conclusion:

Deafblindness/MSI is a rare condition creating extreme difficulties for these individuals. This rare sensory impairment condition affects communication, movement, mobility and the ability to access information. Janssen, Marleen and Rødbroe, Inger. (2007). Together these issues significantly impact the development of social skills by these individuals.

As part of an effort to develop individually based intervention plans for these individuals, it was deemed a priority to develop a system to assess their current social skills. This paper describes the development a Social Skills Check List for Deafblind/MSI children, previously unavailable in India.

The primary researcher is currently developing a language tool to assess the language level of Deafblind/MSI children to correlate with the social skills assessment. This research will help the teachers and caregivers of deafblind/MSI children better understand the difficulties faced by these children. Consequently with better knowledge and understanding, more appropriate efforts can be undertaken to enhance their language and communication skills. The consequence will be improved opportunity for education, successful family living, and integration within social society.

Partial Example of the Check list for assessing the Social skills of deafblind/MSI children

| Question Number | Social Skills                          | Always | Sometimes | Rarely | Never | Not applicable |
|-----------------|--|--------|-----------|--------|-------|----------------|
|                 | Self( 1 of 12 skills areas)            |        |           |        |       |                |
| 1               | Functions as if no one is around       |        |           |        |       |                |
| 2               | Functions as if he is in his own world |        |           |        |       |                |
| 3               | Do not look at while communicating     |        |           |        |       |                |

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## **DbI Pre-conference on Usher Syndrome**

The Holiday Inn, Belfast, Ireland  
3rd & 4th November, 2014

### **Call for Expressions of Interest**

The pre-conference presented by the DbI Usher Network will be held on 3rd and 4th November prior to the DbI Acquired Deafblind Conference in Belfast, Ireland. We are planning an exciting programme concentrating on the Acquired Deafblind Conference theme of "Live, Love and Laughter".

Confirmed speakers so far include:

Professor Andrew Webster, Professor of molecular Ophthalmology UCL, consultant ophthalmologist, Moorfields Eye Hospital. Prof. Webster will be presenting a clinical perspective on Usher and treatments.

Professor Maria Bitner-Glindzicz, Professor of Clinical and Molecular Genetics UCL will lead a presentation on current Usher research.

Liz Hodges and Liz Ellis, University of Birmingham, will present the results of their research project: Life and Change with Usher.

Megan Mann, Sense UK will present 'Usher, An Emotional Journey'.

Mark Dunning, USA will present on the Power of the Usher community.

Please register your interest in attending this pre-conference by email to the Usher Network: [ushernetwork@googlemail.com](mailto:ushernetwork@googlemail.com)

## **Life, Love and Laughter**

Registration is now open for the 10th Dbl ADBN Conference, 4th - 7th November at the Holiday Inn, Belfast, Northern Ireland

Delegates can register for the conference on the Sense website [www.Sense.org.uk](http://www.Sense.org.uk) where they will find the registration form and a link to the Conference hotel to book their accommodation.

The fees for the conference are:

**Full delegate rate: £420**

**Deafblind Delegate rate: £320**

**Communication Support delegate rate: £320**

The fee includes conference pack, the Welcome reception, the Gala dinner, lunch and coffee breaks every day.

The day delegate rate is £95 per day and includes a conference pack, lunch and coffee breaks on the day attended.

For questions about registration, please contact [Alexa.roseblade@sense.org.uk](mailto:Alexa.roseblade@sense.org.uk)

For questions about the programme, please contact [Liz.duncan@sense.org.uk](mailto:Liz.duncan@sense.org.uk)

The programme is available on the Sense website and will be added to over the coming weeks, along with information about travelling to the Conference.

There is also a link to tourist information about Northern Ireland and some special offers for people who would like to arrive early or stay on after the conference.

## **Securing a place for deafblindness in the UK's international development policy**

**James Thornberry, Director of Sense International1**

70% of the estimated 1 billion people, who live with disabilities, live in developing countries. The fact that in many countries rubella is still not part of the routine national immunization programme means that a significant number of disabled people are deafblind. Living with deafblindness in a developing country means you are far more likely to live in extreme poverty and will struggle to access education, employment and this will affect the economic prospects of the entire family.

However, these barriers aren't the only challenges facing disabled people in developing countries. Many will encounter social stigma and prejudice as a result of their disability and particularly in rural communities understanding and acceptance of disability can be low. We know this from the work we do supporting deafblind people in East Africa and Bangladesh.

The Department for International Development<sup>2</sup> (DFID) is responsible for overseeing the UK's aid efforts in 27 countries and accounts for 0.7% of GDP spent. It is considered a world leader in international development. Remarkably, despite the large number of people affected by disability in developing countries, DFID has no policy or strategy on disability.

The function of the Select Committee is to scrutinise the work of DFID and to make key recommendations around its work. MPs from all political parties in the UK are represented on the committee. This year the International Development Select Committee conducted their first ever inquiry into disability and development. We are hopeful that this will go some way to ensure that deafblind people in developing countries will be able to benefit from substantially more international aid than before. The purpose of the inquiry was to investigate how the Department for International Development is addressing the needs of disabled people with its £11.3 billion budget and to make recommendations on how it can improve its response to the needs of disabled people. A range of experts provided evidence to the committee with specialism's including disaster relief and employment.

Edwin Osundwa, the country representative for Sense International in Kenya<sup>3</sup>, gave evidence to the inquiry and we were delighted to secure a mention of deafblindness on the first page.

"I hear and experience cases where a mother who has given birth to a deafblind child [...] has to quit her job because she has to take care of her deafblind child. That becomes a double tragedy for the family, because that mother stops earning a very important income that would sustain the rest of the family members."

"As soon as the mother stops working, in most cases the husband may desert that family. That compounds the problems that such a family experiences".

The committee has now published their final report and DFID will have the opportunity to consider which recommendations to adopt.

Of the 38 recommendations made in the report the Select committee emphasised the need to have a DFID strategy for disability to ensure it is included in all its overseas offices. At present of the 27 country strategy reviewed only 2 had disabilities mentioned with meaningful targets. We recognise that Disability and development isn't an easy area to tackle however one of the challenges Sense International often face is identifying and finding deafblind children who are often hidden living extremely isolated lives. They will often be shut away from their local communities, having received no formal education and little healthcare. Actually finding these children and making sure that they can benefit from international development programmes can be extremely difficult. This is not just limited to deafblindness but other disabilities as well.

This is why DIID must have its own strategy so that £11.3b of UK international aid can be utilised by deafblind and disabled people as a right, not as charity. The particular set of barriers that all disabled people confront mean that we cannot expect this group to just be absorbed in general aid or international development programmes.

Instead, with this set of recommendations from the select committee we have a realistic schedule for change. A more ambitious commitment to disabled people from

a donor of DFID's size and influence can have a transformational impact on the lives of millions of disabled people. Disability inclusive aid will ensure aid is targeted at those who will benefit the most.

## **Geoffrey Atieli – leaving Sense International (East Africa)**

**Geoffrey Atieli, the Regional Director for Sense International (SI) – East Africa, will be leaving the organization on the 31st July 2014, after more than 11 years of service**

In February 2003, Geoffrey was appointed to be the Development Manager (and soon after as the Regional Director) for SI - East Africa, an organization that he proceeded to establish with a team of colleagues in Kenya, Uganda and Tanzania. SI - EA became the 4th SI Regional office after India, Latin America, and Romania. With Geoffrey's guidance SI - EA developed from small beginnings to become an organisation capable of managing large statutory grants delivering tangible improvements to the lives of many hundreds of people who are DeafBlind across the region.

For example the parents of deafblind children in each of the countries formed associations engaging their respective governments (especially of Uganda and Kenya) to claim equal rights for their deafblind children in the provision education and health. Indeed, their success has been such that the Parents' Associations of Uganda and Kenya have successfully influenced the implementation of the education policies for deafblind children in those countries. Secondly, working with UK Government money, SI with local NGO partners developed for the first time a home based education service for more than 600 deafblind children and young adults across the three countries using a Community Based Rehabilitation approach. Where institution based education is not accessible or appropriate to the child's needs this approach is now being scaled up as a model for future implementation across the three countries. Equally, under Geoffrey's guidance the number of schools with deafblind units in the three countries has more than doubled from 10 schools in 2003 to 22 schools in 2014. Lastly, since the SI offices have been established in East Africa there have been significant gains in getting structural change embedded into legislation and policy with school, home based and vocational curriculum developed and adopted and in conjunction with Kentalis and Kyambogo University, Uganda the first DeafBlind teacher training course in Uganda. Geoffrey says "The gains made this far are only a drop in the ocean but they have been possible because of a highly dedicated and selfless field staff of Sense International and partners in each country. The enormity of the needs of deafblind people in East Africa cannot be underestimated, and the challenges ahead are equally enormous, but doable".

James Thornberry (Director of Sense International) notes that "Geoffrey's response is self effacing and modest emphasising the work of his team and partners in the achievements and what still needs to be achieved. Geoffrey will remain a highly popular and gregarious colleague always available to engage with deafblind people

at every feasible level, even when outside of Sense International. We know the East African DeafBlind community and SI will continue to draw on his knowledge, inimitable skills, warmth and generosity. “

We know everyone will join us in wishing Geoffrey all the best for the future and whatever path he chooses he will succeed in.

Kind Regards to all our international colleagues

**Gill Morbey**

**CEO Sense and Sense International**

**President of Dbl**

## **Secretariat News**

### **Meetings**

In March 2014, the Dbl Management Committee met in Bucharest, Romania for the first meeting of the year where the handover of the Secretary's position took place between Elvira Edwards and Matthew Wittorff of Senses Australia. ManCom also took the opportunity to tour the conference venue for the 2015 Dbl World Conference and meet with representatives from the Local & Scientific Planning Committees.

### **Conferences**

9th Australian Deafblind Conference – Sydney, June 2014

Dbl sponsored an exhibitor booth at the National Australian Deafblind conference in Sydney to promote Dbl to delegates. Following the success of the promotional offer to invite new Individual members to join Dbl for 5 Euros for a 1 year period in Lille, a similar offer was extended to delegates at the Australian conference. Dbl welcomed 27 new members from Australia and New Zealand.

### **The 10th Conference of Acquired Deafblindness Network**

The Acquired Deafblindness Network Conference will take place from 4th – 7th November 2014 at the Holiday Inn, Belfast. The conference theme is “Life, Love and Laughter”. More details can be found at

<http://www.deafblindinternational.org/conferences.html>.

### **Dbl World Conference 2015**

Registrations are open for the Dbl World Conference 25-30 May 2015, with the low registration fee deadline and the abstract submission deadline in November 2014.

The local organising committee have negotiated a significant discount at the JW

Marriott Bucharest Grand Hotel, where the conference will be held, so please be sure to take advantage of this terrific deal. Please visit the conference website for up to date information <http://www.dbi2015romania.com/>. The Dbl Board, Management Committee and Annual General meeting will be held immediately prior to the World Conference.

### **Dbl European Conference 2017**

The date has been set! 4th – 8th September 2017! The conference will be held at the Aalborg Congress & Culture Centre in Denmark [www.akkc.dk](http://www.akkc.dk). The Dbl Secretariat will share more news about this conference with members via email and through the Dbl website and Facebook page.

### **Dbl World Conference 2019**

In February 2014, we called for Expressions of Interest (EOI) to host the Dbl World Conference 2019. We look forward to announcing the new host country at the World Conference in Romania next year.

### **Nominations**

Earlier this year members were invited to nominate people for the role of Dbl President and Dbl Vice-President(s) as well as Board member positions. Corporate members and Dbl Networks will be invited to vote in the electronic ballot which will begin in November 2014 and finish in February 2015. The Nominations Committee will summarize and prepare the results for ratification at the May 2015 Annual General Meeting. All nominated officers will be notified of the outcome at this time. The elected officers will then be ratified by the full Board. In order for your vote to be accepted, Dbl Membership must be paid by November 2014.

### **Membership**

Thank you to the many members who have renewed their membership to Dbl this year. If you haven't yet renewed we encourage you to do so online at <http://deafblindinternational.org/membership.html> or contact the Dbl Secretariat for more information at [secretariat@deafblindinternational.org](mailto:secretariat@deafblindinternational.org).

### **Keeping in Touch**

Do you have information you want to share with others or are you looking for a contact in a faraway place? We are happy to facilitate communication amongst Dbl members and our contacts across the world so please keep in touch with us and let us know if we can help.

## **Dbi Board Membership 2011-2015**

### **Management Committee**

The Management Committee for the 2011-2015 period includes the two elected offices (President and two Vice-Presidents), Immediate Past President, Treasurer, Information Officer, Secretary and Development Officer:

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#### 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

Lord Colin Low

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World Federation of the Deafblind

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## **An independent and meaningful life with deafblindness**

Deafblindness has fundamental consequences and often influences every aspect of the lives of those affected by it, yet an independent, meaningful and active life is perfectly possible. Kentalis has all the knowledge required to help and supervise deafblind people in this, allowing them to give substance to their life in a way that suits them and to make use of their talents.

Paul is 26 years old and suffers from Usher type 2. In daily life, he provides children at primary schools with information about his deafblindness and he works as an administrator at the Kenniscentrum Doofblindheid (Deafblindness Centre of Excellence) of Kentalis. Music is very important for Paul: 'My passion for music makes me feel that I belong; it determines who I am, provides me with a sense of identity and a way of expressing myself'.

### **Deafblindness Centre of Excellence**

Our Deafblindness Centre of Excellence continuously develops and shares knowledge in the area of diagnostics, education, care, work and supervision, both in the Netherlands and internationally. We work closely with the University of Groningen and Marleen Janssen, the only deafblindness professor in the world.

### **About Kentalis**

In the Netherlands, Kentalis is the pre-eminent specialist in the area of diagnostics, care and education for children, young people and adults with auditory or communicative disabilities, whether they are deaf, (severely) hearing impaired, deafblind or have trouble with language or speaking. We focus on their optimal participation in society. Kentalis has 20 schools for special needs education, 80 care and diagnostics locations and 6 audiological centres. Kentalis employs 4,600 people.

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