

## **DbI Review**

Number 52 • January 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.

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## **A message from the president**

Dear Friends and Colleagues,

We had a wonderful European Dbl conference in August in Lille. Over 300 delegates listened and contributed to some great discussions. You will be able to read more in depth in the Review but huge congratulations must go to Jacques Souriau and the scientific committee members and Dominique Spriet and Valerie Taggiasco for the local planning.

All conferences have their memorable moments for different reasons. There were many on this occasion but for me presentations by deafblind people themselves are always the most rewarding. Deafblind people courageously share their issues and present us with challenges and learning opportunities in unique ways. We just have to make sure we are listening. One such magical moment was the circus of course with Valerie's son performing alongside his father. Who would have missed that moment?

As usual Dbl tries to make the most of the limited times we can get together so we always take the opportunity to attach our meetings to events. This was no exception and we held our Management Committee, Board and AGM meetings prior to the conference. It was great to welcome some new members to our Board and we introduced two new roles. One for development and a second to try and put more focus on research. I think both were well received.

We were delighted that Dennis Lolli was able to represent Perkins International during the Board meeting and the Management Committee were able to thank Debbie Karasinski CEO of Senses for all the hard work Elvira and Bronte put in to the Secretariat. Geir Jensen and Sanja Tarczay joined us from the World Federation of Deafblind for part of the Board agenda so we really made the most of the time available.

We are now looking forward to the Acquired Deafblind Network conference in Belfast, November 2014 and planning for the world conference in Romania in May 2015. On behalf of Dbl, a huge thanks to everyone who is currently working on these important conferences. You give your expertise and time to put fantastic opportunities together for us. We 'just turn up' so in case we haven't properly acknowledged all that people do, thank you.

Kindest regards to all  
Gillian Morbey

## Editorial

Dear Friends,

Once again we have another eclectic array of articles covering a broad spectrum of deafblindness related activities. Many of the articles included are presentations made at recent conferences that will be of interest to the general membership. This edition also highlights exciting program developments and educational activities happening throughout the world.

The European Conference in Lille was the major Dbl event that occurred in 2013. The organizers are commended for a wonderful conference which (most everyone attending agreed) succeeded in satisfying the ambitious theme of discussing and sorting out the commonalities across deafblindness and learning from each other. Ole Mortensen's conference wrap-up plenary presentation does an excellent job of describing that.

Scattered through this edition you will find various conference presentations, some of which I targeted during the conference; others were sent to me unsolicited from the authors. I received several other workshop presentations that will appear in future editions.

What stands out for me in this edition are several very personal stories delivered during the conference. Sven Kolset's story about his son Torgeir, 'An Exceptional Fellow' is particularly heart-warming, and describes the importance of the family team in raising a disabled child through to adulthood. On another family tack, Sabine Kersten speaks about her life as a sibling to a brother with Usher Syndrome and the emotional toll that it has taken. Who could not be impressed with Emma Boswell, a person with Usher Syndrome, describing first-hand the aspects of 'denial, shame and pride' that she and other people experience with Usher Syndrome. Interestingly, Emma uses these personal experiences to assist her in her role as a SENSE consultant.

While at the Lille conference I had the opportunity to see a Focus Group performance by the Kalorama Theatre Group 'Toneel Mooi Uitzicht (Beautiful View)'. The director Casper Schimmel prepared an article 'Our Deafblind Actors are an Inspiration' which you might find quite fascinating.

A feature of each edition of Dbl Review is a section with reports from the networks, which now totals 12. Many of the networks met during the Lille Conference, and for some of them, like Rubella and Usher, it was an opportunity to regroup. For those such as CHARGE and Communication, it provided the possibility to outline their past activities and make new plans. For the new Youth Network, this was their first opportunity to connect and develop their international membership. Check out their reports.

I think you will find very interesting the article from Signo Foundation in Andebu, Norway, about the world's first Multi-Sensory Church, Tomaskirken. I had the opportunity in November 2012, while visiting the Signo Dovblindesenter in Andebu, to see the fellowship tapestry which is now at the entrance way of the church. It might interest readers that two individuals known to many (Riitta Lahtinen and Russ Palmer) were married in this church recently. Riitta and Russ are also co-leaders of the Social Haptic Communication Network.

In this edition, several articles from Dr Tim Hartshorne (and colleagues) related to CHARGE Syndrome, are featured. The article 'Self-Regulation in Individuals with CHARGE' begins a series of at least five research articles concerning self-regulation issues with this disability. Additional articles, to be published in future editions, will provide details about the four dimensions (cognition, behavior, emotion, and physiology) of the self-regulation model developed by Dr Hartshorne and Dr Jude Nicholas. The other CHARGE article 'Needs of Children with CHARGE', was Dr Hartshorne's keynote address at the recent Brazilian 'Holding Hands' International Forum in Sao Carlos, which I had the pleasure of attending.

At this point we are considering that the July 2014 edition of Dbl Review will have a theme, 'The Sky is Not the Limit'. We will be looking for articles about examples of professions, special activities, note-worthy accomplishments, etc, demonstrated by deafblind people. Of course there will always be room for other materials as well.

Happy reading,  
Stan Munroe

## **Bernadette Kappen reports:**

What is special about Dbl? When I think about this question the words support, knowledge, caring, friendships, expertise and fun come to mind. The Dbl European Conference in Lille saw these words in action every day. It was a time to renew friendships and learn new things in the field. Looking around the large conference room each morning you would see many familiar faces but this time there were so many new people in the field of deafblindness. Growing the number of professionals around the world is so important in providing good programs and services for individuals who are deafblind. The members of the scientific and host committees did an outstanding job meeting the professional and personal needs of the participants. I know I can say that each participant is so grateful for all that was done to make the time in Lille so special.

Dbl is not just the conferences. It is the ongoing connection with members around the world. I hope you will visit the website on a regular basis and feel comfortable contacting Management Committee and the Board if you have questions or want to get information about resources.

Staying connected helps us learn about new resources and this motivates us to continue our efforts to provide the very best programs to individuals who are deafblind.

Bernadette

### **Carolyn Monaco reports:**

Happy New Year! 2014 is already shaping up to be another eventful year for Deafblind International.

With the 2014 winter Olympics in Sochi taking place in February I am once again reminded of the parallels between two of my passions, Dbl and the Olympics. My first recognition of the parallels dates back to the early 90's while participating in CDBA's proposal writing to host a Dbl International Conference here in Canada. Many times during our efforts to bring that event to fruition the members of our committee used terminology such as "a bid to host", "opening ceremony", "awards", "hosting the world", "flags" and of course "the spirit of international friendship", all of which we had previously associated with the hosting of Olympic events.

The great thing about the Olympics and Dbl is that you don't always have to be there physically to enjoy and benefit from the wonderful things that happen there. The various media options will keep us in touch with our athletes in Sochi and similarly Dbl's Review magazine and website provide us with access to those events we are unable to attend and some of the information and experiences shared there. In 2014 I hope you will think about introducing a colleague, an individual who is deafblind, an organization or a family member to Dbl so that they can cheer on the world of deafblindness and benefit from the international spirit.

Carolyn

### **The Dbl CHARGE Network reports on their successful CHARGE PreConference**

**Lille, France, August 24, 2013**

On August 24th, 2013 the Deafblind International CHARGE Network held its (first) pre-conference in advance of the 8th European Dbl conference held in Lille France. It was organized by the task group of the Dbl CHARGE Network: Gail Deuce (Sense UK), Martha Majors (Perkins, USA) and Andrea Wanka (Stiftung St. Franziskus, Germany).

Forty-seven individuals representing Great Britain, Sweden, Norway, Germany, the Netherlands and Taiwan participated in the conference

The day began first with introductions followed by the viewing of photos of five different children and young adults with CHARGE Syndrome from the German photographer Robert Bühler. Following this, Martha Majors, who could not join the preconference in person, gave some greeting words by video to the participants. The two main topics for the PreConference were Social-Emotional Skills and Communication. The morning session focused on social-emotional skills. Sonja Friberg from Sweden gave a presentation about the Nordic Network of professionals specializing in CHARGE Syndrome. Following Sonja, Gail Deuce gave further insights through a case study. A short break gave time for the participants to come together and get to know one another.

After the break, the participants were divided into four discussion groups, moderated by Sonja, Gail, Andrea (Germany) and Steve Rose (Sense UK). Each group discussed the social-emotional aspects of people with CHARGE and presented their discussions before lunch.

After lunch we focused on communication. Odette Haubrich (Sense UK) and Steve Rose gave, in the first presentation, an overview about the unusual aspects of communication exhibited by persons with CHARGE Syndrome. The second presentation on the topic of communication was a case study made by Andrea Wanka. As during the morning Session, the same four discussion groups came together and then shared their discussions.

In addition to the planned agenda, there was much more informal sharing during the day. Examples included: the sharing of a wonderful video from Eva Karlsson (Sweden) showing how a child with CHARGE learned to ride a bicycle in her own way; information about a book by Svein Olav Kolset from Norway on the life of his now 38 year old son with CHARGE; information about the practitioners' portfolio from Sense, and information about the upcoming Danish CHARGE conference planned for next year.

This first preconference of the Dbl CHARGE Network was very exciting for the participants and also for the planning committee. We hope to repeat this wonderful event in advance of the next World conference in Romania in 2017.

For further information or to become a member of the Dbl CHARGE Network please contact [Andrea-Wanka@dbicharge.org](mailto:Andrea-Wanka@dbicharge.org).

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**Dbl President Gillian Morbey officially opens the 8th European Conference on Deafblindness**

It's wonderful to be in France again; my first time here on deafblindness business since attending the 1987 Conference in Poitiers. I'm well aware of the significant and continued contribution from our French colleagues in establishing services for deafblind people as well as contributing to the development of knowledge about communication through the hosting of several communication seminars in Paris. So I am absolutely sure this Dbl European conference jointly hosted by ANPSA, the French National Deafblind Association and CRESAM, the French Network for Deafblindness, will be an outstanding success.

I'd like to say a few words about the conference theme 'Identities and Changes - Commonalities across Deafblindness' and how much this resonates with Dbl. It's a thought provoking theme which I would expect from Jacques Souriau and the members of the scientific committee. They have done a great job in pulling together such a range of interesting presentations and discussions around this topic.

I guess we will all draw our own meanings from the concept, but I was struck by the sub text 'commonalities across deafblindness'. The best and most sustainable movements and organisations are often started from the bottom up because there is a need, there is a common interest. And that's exactly how and why Dbl and many of the organisations here today began. The early beginnings of Dbl came about because isolated educationalists across the world were looking for the 'answers' for working largely with the rubella group of deafblind children in the 1960's and 70's. Initially the organization was called The International Association for the Education of Deafblind or IAEDB.

How wonderful it was that a small group of professionals 'cared' enough to try and do something for these children. They saw the commonalities among those very challenging children and decided to do something about it. Similarly, we see that mirrored in the recent past where we were told that there was no such thing as CHARGE syndrome and yet we all knew we were supporting children with similar traits. Finally the clinical world agreed and accepted that there was a syndrome designation for this CHARGE population.

Our greatest commonality is probably communication; of course now we understand so much more than we did in the 1970's. Because we take it for granted, we often fail to appreciate how skilled our practitioners are; and even more so, how brilliant the deafblind people are to receive a touch or a sign in so many variations and gather meaning from these abstract modes of communication. Perhaps we are only reminded of how far we have come if an external visitor comes to our centres and marvels at the speed of touch/sign and the meaningful response that comes back! Just as the professionals were discovering these commonalities, so were the parents and families. One of the key identities of all our organisations is that we work in partnership with families who are just as important, if not more so, than the professionals. In those early days parents struggled for knowledge; they saw the commonalities amongst their rubella children, displaying similar physical characteristics, and oh yes - the hyperactivity and the sleepless nights! And they decided to do something about it.

Then there were the deafblind people themselves; so much harder for them to come together as a group. But with the development of technology, deafblind peoples'

world shrank as well and they increasingly found their identity through many organisations, including the World Federation of the Deafblind (WFDB) and the Dbl Acquired Deafblindness Network.

Finding these commonalities is so important for the profession and discipline of deafblindness; but for deafblind people it's much more than that. It is building links, developing friendships and relationships; knowing that either as a family member, professional or deafblind person, we have a community. Put simply we are not alone!

This conference will attempt to bring these elements together by bravely tackling subjects with professionals, parents and deafblind people all taking their equal place in presentations and participation. Jacques Souriau noted that one of the aims of this conference is to 'show and describe the resilience of deafblindness as a unique disability'. I have absolutely no doubt this conference will do that.

Turning to the main theme 'Identities and changes' I can only imagine the huge range of discussions that will develop; philosophers and psychologists have studied the theme of identity for many years. The main plenary speakers will tackle subjects that have long been difficult for our deafblind world: emotionality, the development of social cognition, how individuals develop their capacities to live their own lives and the role of narratives in building individual identities. These complex topics I know will stimulate huge debate.

I was at an art exhibition not so long ago called 'Outsider Art'. The paintings and sculptures were produced by disabled people from Japan. The event was unbelievably moving; throughout the exhibition one could see the artists' struggle with identity, narrative and emotionality in one form or another. One artist constantly produced self-portraits that started quite large; then by the 10th or 11th painting his self-portrait was only slightly bigger than a postage stamp. Another artist made dolls of her long deceased mother growing larger with each piece. A sense of identity, understanding your emotionality and telling your story does not come easily. I understand that the Lille Museum of Modern Art, while featuring Picasso the famous outsider, has a new wing dedicated to 'outsider art'. Perhaps in a similar way to Picasso (the original outsider who became celebrated), we can argue that the 'outsider' world of deafblindness has much to offer not just to the wider field of disability but to society as a whole.

We knew that our world was special in the 1950's and 60's when we were starting to come together in family groups. This was the beginning of the country support organisations and the emerging International Association for the Education of Deafblind which later become Dbl. We weren't always able to describe our identity and detail our commonalities but we knew they were there. I feel sure this conference will remind us why we are special and perhaps we will be able to answer Jacques Sauriau's point about the resilience of deafblindness.

Finally I can't speak to the resilience of deafblindness but I would formally like to note the resilience of the organisers. I must thank Dominique Spriet, Chair of the Local Organising Committee and long-time friend who has done a fantastic job with her team of willing volunteers. On behalf of Dbl I am indeed privileged to thank Jacques Souriau, Valerie Taggiasco President of ANPSA, and for the work of the



scientific and planning committees, respectively. They have undertaken a huge amount of work. Thank you also to all the sponsors and the City of Lille along with I'm quite sure hundreds of people who will make this conference successful. I look forward to meeting old friends and welcoming new ones over the coming days. On behalf of Dbl it's my privilege to thank the organizers and declare the 8th Dbl European conference officially open.

## **Commonalities across deafblindness – learning from each other**

**An edited version of the final plenary at the European Conference on Deafblindness in Lille, presented by Ole E. Mortensen on behalf of the Scientific Committee.**

When the Scientific Committee started out the work for this conference we quickly decided to address the issue of the distinction that exists between acquired deafblindness and congenital deafblindness. The two 'sides of deafblindness' have been developing over a number of years now, but without much interaction. We believed we should focus on the potential synergy between the two that has not yet been explored satisfactorily.

Conferences on deafblindness have always had to deal with this duality, since Dbl is an organisation for professionals representing both groups of deafblindness. There has always been a sort of sibling rivalry: "If they get a plenary, we want a plenary. If they get 10 workshops, we want 10 workshops."

### **Let's focus on what unites us!**

Therefore, the Scientific Committee wanted at this conference to focus more on what unites the groups rather than what separates them.

The following represents the Scientific Committee's thoughts on this topic as interpreted by me. I will take my starting point in the work and the discussions we have had in the committee and add my own thoughts on it.

We are not trying to eliminate differences or pushing towards finding commonalities that are not there. But we on the Scientific Committee do feel that there are commonalities, or at least that there might be commonalities, that we have not found yet because we have not been looking for them. It seems a pity if we do not make the effort to explore, what we might gain from a closer collaboration between the two groups.

### **Many different individuals**

Deafblindness is a professional field which encompasses many different individuals with very different age, competences, impairments, situations etc. However, they all

share one important feature: They can't see nor hear very well. Apart from that, do they have anything in common?

Many say that the commonalities between acquired and congenital deafblindness are few and hard to find. There may be several reasons for this.

### **Highly specialized professionals**

One reason is that we, as professionals, are so specialized today – and we love to feel highly specialized. We are specialists in communication development, in orientation and mobility, in old age deafblindness etc. This specialization is part of our professional identity and of the way we see and perceive ourselves.

This has been emphasized by the fact that over the years we have had to advocate for deafblindness itself being something special – a unique disability different from hearing impairment and vision impairment and with an impact that is bigger than the two put together.

We are all very much immersed in our tradition and understanding of ourselves as highly specialized professionals in a small and very specialized field. Still, we have no problem gathering inspiration and knowledge from fields sometimes far from our own and taking part in inter-professional learning.

But as soon as it comes close enough to our own field that we see similarities, we start to pay more attention to the differences instead. The differences stand out and seem larger than they are because there are similarities as well. Danish neuroscientist Kjeld Fredens puts it this way: “The more we know about a subject, the harder it is to think new things!”

### **Similarities**

So let's try and focus on the similarities. What can we say we have in common?

First and foremost, both acquired and congenital deafblindness create massive problems in relation to communication, access to information and mobility.

But there are also a number of other themes that we find on both sides. This has also been seen during this (Lille) conference, where we in the Scientific Committee have set out to find them. All nine of us have only attended workshops in the other field than the one we work in normally – just to see what, if anything, we would recognize from our own experience.

When comparing our notes from the workshops with what we have heard during the plenaries, we get a list of themes that are clearly relevant for both sides. Among the themes on this list are the following:

Denial (in the person, family or society) shame, pride; Need for empowerment; Isolation; Deprivation; Danger of being disconnected; Helplessness; Aggression; Withdrawal; Being labelled; Being met with low expectations (abilities are often underestimated); Feeling of being different; Reactions in and consequences for siblings to people with deafblindness; Both the need for and the threat against quality of life; Need for tactile and alternative communication; Need and wish for pushing the limits; Neither persons with acquired nor congenital deafblindness

necessarily see themselves as deafblind first – as opposed to what most other people do.

And as for the services available for the groups there are also a number of similarities, such as the lack of knowledge and awareness; Need for a person centered approach; High ethical standards necessary in professionals; Need for good staff training; Use of various assessment tools; People with acquired deafblindness are often considered experts in their own life. So should people with congenital deafblindness. But how do we find a way for them to express this?

### **Similar problems, different solutions**

It is obvious that even though two persons may share a similar problem, the approach to solving it may be completely different depending on the person's situation and disability. A 10-year-old deafblind child born two months prematurely with a number of neurological and maybe physical problems in addition to the sensory impairment have problems with communication, information and mobility. These problems are similar for the 88-year old blind woman when she loses the last of her hearing. There is a commonality in the characteristics of the problem, but we need to use different approaches for solving it.

Jacques Souriau, the president of the Scientific Committee said it beautifully, I think: What is unique to deafblindness is this question: "How can two minds connect in a world where most everything happens through vision and hearing."

Some commonalities in deafblindness are shared with many other groups of people with disabilities. Other commonalities are shared with all human beings. What makes sense for us here is to look at the commonalities in practice, since that is what these conferences are aimed at: improving the practice of the participants.

### **Direct and indirect learning**

Learning comes in many shapes, colors and form. Sometimes we do not even know from where our knowledge comes – it just is there.

Let us take a look at the process of transferring knowledge at conferences, since this was the topic here in this conference. There are two ways of transferring knowledge into own practice:

- Direct – as in "this approach or intervention can also be used by me"
- Indirect – as in "this way of thinking can help me think up my own approaches or interventions"

The information presented at workshops at our conferences often is: "this is what we have done" or "this is what we have found out". Our target group or intended audiences at workshops are most often much like ourselves with similar backgrounds, who face similar challenges and tasks, and who may use the information presented directly in their own setting.

This is a 'copy-paste' approach. Not much translation is needed here. An art project for congenitally deafblind children from Holland or a network group for men with Usher 2 from Denmark can be put in practice the week later in Italy.

It gets very practical and relevant – but it limits the interest to colleagues in similar situations.

### **Translating knowledge**

However, we rarely try to take our experience and knowledge and the learning points one step up to a more general level and thus remove us slightly from the specific situation in which the knowledge has been developed.

This is what would make it relevant for others than your own colleagues as well. This was why the Scientific committee decided to have presenters from outside the field of deafblindness give lectures as plenaries on central and common important topics – but with no direct ties to deafblindness of any type.

The challenge here for us as participants has been to make the information part of our own knowledge base and implement it in our own practice – translate the knowledge to something that is relevant for each of us.

### **255 work days**

Workshops are a big part of the conference program in our field. There were a total of 82 workshops at this conference. 340 people have each participated in six workshops of one hour. This amounts to a total of 255 work days – an enormous investment of time.

Therefore it is essential to make the workshops really work. Instead of thinking about making sense to someone like ourselves, we should start thinking about sharing our knowledge with someone who does not share the approaches, the way of thinking, traditions and culture in our specific field.

And when we talk about knowledge sharing it is not enough to say, “our workshop is open to all, therefore I am sharing my knowledge”. It is not as simple as that. It requires something from both. It takes two to tango!

There needs to be a motivation from the person seeking the knowledge. This motivation is present, judging from the questionnaire survey that we did earlier in the conference. Around 90 % of the ones who answered said that they feel there is something to be learned from the other side of deafblindness. This is highly encouraging.

But there also needs to be a willingness to make the effort to share one's knowledge. It has to be a conscious effort and it takes more work and preparation than if you are to tell your story to your own colleagues. On the positive side is that presenters will often gain by getting more and more varied feedback on your project to take home, making it well worth the effort.

### **Out of the comfort zone**

We have been conducting conferences and seminars the same way for many years now. It feels good, safe, and recognizable. But maybe it is time to get out of our comfort zone – like Svein Olav Kolset said in his presentation “An Exceptional Fellow” and start working on it.

The time is right for a change. The Norwegian psychologist Anne Nafstad, who has worked for many years in the field of deafblindness, recently said: "Professionals are becoming more and more individualistic. The culture is breaking up – the culture of a strong collective identity. It is being replaced by a new and more independent or autonomous approach questioning the prevalent practice and using new pedagogical methods from other fields."

Maybe this will mean that the old way of doing things – which may include being sceptical towards 'the other field' along with a bit of laziness – will change into a culture that is more including and open and generous and innovative when it comes to knowledge sharing.

If Dbl and their members really want this change, here is a golden opportunity to promote this change which should then benefit the field of deafblindness as a whole.

Ole Mortensen

Member Scientific Committee, 8th Dbl European Conference

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## **Dbl World Conference 2015**

### **Romania welcomes you to Bucharest in May 2015 for the 16th World Conference on Deafblindness**

I am extremely pleased to invite you to Bucharest Romania where the 16th Dbl world conference will take place May 25 – 30, 2015 at Hotel JW Marriott.

Bucharest is the capital city of Romania and also its largest metropolis with a population of 2 million people. In my parent's youth, Bucharest was known as the little Paris. Over time the city has gone through many changes, creating an interesting blend of old and new.

I am sure some of you are familiar with some notable Romanians. One will remain unmentionable, but there are others that have made Romania famous: George Enescu the great composer; Brâncuși the famous sculpture; the playwright Eugène Ionesco; Angela Gheorghiu the opera singer, the tennis player Ilie Năstase and Nadia Comăneci the gymnast. I don't mean to forget the infamous and somewhat mythical Dracula!

As a passionate activist in the field of deafblindness I wish to add something extremely important. If everything I have mentioned so far has not convinced you to register for the next world conference in Romania in 2015, I'm sure what I will share with you now will definitely influence you.

In 2000 when we registered as a local NGO working with and for deafblind people in Romania, we had to start from scratch. We were told there was no person with deafblindness in Romania. However we knew that most of the people we are now working with were in long stay hospitals or in the best scenario, at home with their

families but without educational support. There was not even a word for deafblindness in the Romanian dictionary.

Without false modesty I can tell you that we have achieved very much in 13 years and we would be pleased to share our achievements with you. So put the dates in your diaries and be prepared for a great conference.

At the same time, your participation is vital to share with us a great celebration of all our work here in Romania. Furthermore it will be a fantastic opportunity for people from Romania with deafblindness, their families and professionals in the field to meet, share ideas and personal experiences with international participants and last but not least, to have fun! I shouldn't forget to say a few words about Romanian hospitality; I am sure that people who have visited us on pleasure or with business will recognise this.

We'll be looking forward to meeting you in Romania in 2015.

Cristiana Salomie

Director, Sense International Romania

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## **What is our future?**

### **Local solutions to common needs**

The central question for the conference will be our future. As the field of deafblindness expands with services to more people in more countries, how do we ensure that deafblind children and adults will receive support which is of a high quality as well as being culturally appropriate?

This conference will take place at a unique time in our history – we are now becoming very clear about the needs created by deafblindness, and know that many of these needs are experienced whenever deafblindness occurs. At the same time, we have developed as a field, to a mature stage in which there are different approaches to meeting these needs, each approach can be excellent in their own way but may be culturally appropriate to a specific part of the world. For the first time, we are beginning to accept that local solutions can successfully meet the needs created by deafblindness. No longer is there just one, best way.

The conference will reflect this exciting time in our development with the opportunity to hear about the range of services and approaches being developed around the world. Please come and join in. You will be learning, exploring, debating; listening, explaining and exchanging ideas and experiences. This is a unique gathering, offering the only chance to meet with colleagues from such a large number of countries. What is our future? You decide.

Tony Best

Chair, Scientific Committee  
Email: [tonybest987@gmail.com](mailto:tonybest987@gmail.com)

## **Life, Love and Laughter**

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

**Belfast, Northern Ireland, November 4-7, 2014**

Check out the websites of Dbl ([www.deafblindinternational.org](http://www.deafblindinternational.org)) and Sense ([www.sense.org.uk](http://www.sense.org.uk)) for further details about the ADBN conference and any pre-conferences, including guidelines for abstracts, registration information and accommodation details.

Theme related conference workshop abstracts are now welcomed and can be forwarded to the attention of Arlene Albert ([Arlene.Albert@sense.org.uk](mailto:Arlene.Albert@sense.org.uk)) no later than March 31, 2014.

The Dbl Usher Syndrome Network has announced November 03 and 04 as the dates for their Pre-Conference to the ADBN Conference. For more information about their program, contact Emma Boswell, Sense National Usher Coordinator ([Emma.Boswell@sense.org.uk](mailto:Emma.Boswell@sense.org.uk)).

If other Dbl Networks are interested in a Pre-Conference in Belfast, contact Liz Duncan ([Liz.Duncan@sense.org.uk](mailto:Liz.Duncan@sense.org.uk)).

## **A Vibrational Approach to Teaching a Deafblind Student<sup>1</sup>**

**The inspirational story of Jessica Cook In the Key of C  
by: Christine Sauv  Guindon**

Jessica Cook was born August 11th 1994, in Welland, Ontario, Canada. Soon after her birth, a rare metabolic condition was diagnosed called Pyruvate dehydrogenase, type 1<sup>2</sup>. Jessica had a severe case which included multiple brain malformations. Jessica had little residual vision at birth, and would not respond to speech. Her brain defects had rendered her functionally deafblind. Her parents were told:  
"Your daughter is blind."

"She will have severe developmental delays."

"She won't speak; therefore, she will never communicate."

The first year was filled with appointments and learning about their daughter's prognosis. They learned about genetics, neurology, and were regulars at their local children's hospital. Jessica wasn't developing normally, and the doctors didn't know

even if she was going to survive infancy. She was a severely brain injured child who could neither respond to sight nor sounds during her first several years.

It is when she was old enough to attend a pre-school program that the magic began as we first observed Jessica reacting to sound. She would not react to voices, but appeared to respond to songs! This girl, who initially was perceived as functionally deaf, was smiling and enjoying her classmates sing!

I met Jessica when she was 8 years old and in elementary school. I was consulted because neither the teacher for the Blind or the Language and Speech Pathologist knew what to do with this 'blind girl' who had difficulty communicating. What I discovered was that Jessica, who could not communicate, had a sign for 'MUSIC'. Also, while she did not appear to respond to spoken language, apparently she heard songs! The one word she responded to was: 'MUSIQUE'.

While she appeared to enjoy music, she objected to loud noises. Her combined sensory loss was also inhibiting her from exploring her world tactually. She seemed to enjoy the company of the children at school, but did not truly interact with them. McInnes and Treffry (1982) taught teachers to work with 'what seemed to interest the child'. Dr. vanDijk (1999) suggested that teachers should use the sensory modality that seemed to best interest a child. My role as the consultant was to help her acquire more language and to help diminish difficult behaviours. Jessica was tactile defensive; tactile cues wouldn't work. She was blind, not attending to visual cues; yet she responded to MUSIC and to SONGS!

Gardner (1993) suggested that we possess many different 'intelligences'. By pluralising the word 'Intelligence', Gardner, wanted educators to teach the students according to their particular learning styles. I had written (Sauvé Guindon, 1999) that if we could determine the dominant 'intelligence', it would then permit the students' interest to be the 'key that would open the world', moving from their Intrapersonal intelligence to the Interpersonal intelligence. The key to Jessica was music and song. Music was the key to unlocking her world.

If music and song were such powerful tools, could they be used to enhance the total communication approach? We sang to her specific songs with tactile cues to ensure she would understand the activities we would be doing during the day at school. She still couldn't tell us which song she wanted to hear, but we did have a way for her to anticipate her daily routine.

Jessica has Cortical Visual Impairment<sup>3</sup>. At first, she was not visually attending to many things other than her favourite musical toys. We used various CVI strategies including music and her favourite songs. We discovered that by using various musical selections while doing vision stimulation, an improvement in her vision occurred. Using music during physiotherapy consequently led to improvements. Norman Doidge (2007 p.xix) wrote in the preface of 'The Brain That Changes Itself', that: "[Scientists] showed that children are not always stuck with the mental abilities they are born with; that the damaged brain can often reorganize itself so that when one part fails, another can often substitute...." And "... that if brain cells die, they can at times be replaced; that many 'circuits' and even basic reflexes that we think are hardwired are not."



Jill Bolte Taylor (2009) explains what transpired to an injured brain in 'My Stroke of Insight'. From this book I understood how we see and how we decode what we see; the difference between hearing, understanding, and interpreting what we hear; proprioception and the movement of the body; the sense of touch; and sensory integration, etc. More importantly, this book taught me not to give up because re-education is possible!

I was starting to understand what seemed to be happening. Music was stimulating her brain! This 'blind' girl was starting to use her vision. This 'deaf' girl was starting to make sense of her auditory world.

Authors like Oliver Sacks (2007) and Daniel Levitin (2007) have given me the inspiration to go further. They help me understand the power of music and how it can stimulate various parts of the brain.

"Musical activity involves nearly every region of the brain that we know about, and nearly every neural subsystem. Different aspects of the music are handled by different neural regions – the brain uses functional segregation for music processing, and employs a system of feature detectors whose job it is to analyse specific aspects of the musical signal, such as pitch, tempo, timbre, and so on." Levitin (2007), p.85-86

So, could vibration of the songs be breaking Jessica's tactile defensiveness to make her 'feel' music all through her body? We believe this has allowed her to discover her outside world using a new sense – touch! Consequently we could now hold her hands and work with her hand over/under hand. We would encourage her to further expand her 'new' world through the sense of touch.

We have witnessed wonderful growth over a short period through integrating her senses. For example, the rain stick toy which, in 2006, she would only respond to auditorily, was now being tracked visually in 2013. With time and effort we were able to have Jessica transfer competencies from one area to another. For example, when we saw she could activate a musical toy with her hand, we worked with her so she could transfer this ability to hit a switch. Cause and effect educational goals were then added to her education plan. From hitting a drum, we taught her to hit a switch! Jessica now has the capability to activate a switch to tell us which song she would like us to sing. She can also sing along with us by activating the switch. Music was permitting her to participate socially and communicate her wants and needs! Music seemed to stimulate all levels of her brain, and the research in this area is proving this.

Levitin (2007) wrote (Page 86): "Listening to music starts with subcortical structures (cochlear nuclei, brain stem, cerebellum) and then moves up to the auditory cortices on both sides of the brain. Trying to follow along music that you know ... recruits additional regions of the brain, including the hippocampus (our memory center) and subsections of the frontal lobe, particularly a region called inferior frontal cortex, which is in the lowest parts of the frontal lobe

Other research also demonstrates that auditory stimulation, while using speech or music, will activate the same areas of the brain.<sup>4</sup> Music, it would seem, was also creating new neural pathways so that Jessica could now comprehend speech! If she understands your request (and it is usually music related), she can answer: 'Yes', by

nodding her head! What is happening neurologically? Where is speech being decoded? Is this due to repetitive musical stimulation? We still have so many questions.

By nodding 'yes' to us, Jessica can now answer when we ask her questions. This has made her more autonomous, apparently given her personal satisfaction, helps her to concentrate and comprehend more than we ever thought this 'developmentally delayed' girl could ever do!

Can music then be used to enhance her quality of life in other ways? We are now exploring music therapy with her by having her listen to sounds played on a harp. Dr. Piché-Séguin composes songs that have a specific rhythm, with specific notes that will resonate to help the body relax and rejuvenate. We are carrying out a trial with a song performed by Dr. Piché-Séguin. So far, Jessica has shown a calming reaction to the song. We are studying this further.

In retrospect, I now understand why Jessica would always greet me by activating a toy piano to the song: 'Frère Jacques'. This was the first song I sang to her when we first met.

In conclusion, music and song have been the motivational links that have introduced her to the world. Jessica understands and more importantly, she is now understood! The research on brain plasticity and malleability has given me a whole new perspective on how to educate and work with multisensory deprived children born with brain malformations. Despite the severity of the brain defects, the key to development is to create new neural pathways through sensory stimulation.

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<sup>1</sup> Workshop presented at 8th Dbl European Conference, Lille France, August 26, 2013

<sup>2</sup> [www.ghr.nlm.nih.gov/gene/PDHA1](http://www.ghr.nlm.nih.gov/gene/PDHA1)

<sup>3</sup> <http://www.childrenshospital.org/health-topics/conditions/cortical-visual-impairment>

<sup>4</sup> <http://www.art-et-science.fr/cerebrart/2008/musiqueetsante.htm>

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## **A Multi-Sensory Church<sup>1</sup>**

**The world's largest vibration floor is booming. Purple rays flash from the ceiling. Heavy incense is spreading through the pews. Welcome to the world's only Multi-Sensory Church**

**By Marit Dehli**

**Photos by permission from Kai-Otto Melau**

Have you ever jumped in your seat during a church service prelude? In the Thomas Church you definitely will when you hear the 54 sub woofers. Powerful amplifiers in the floor make the sound vibrate; church music must be felt! The light organ in the ceiling is blinking in pace with the rhythm rising from the floor boards. During worship people are free to lie down on the floor, be filled with the sound and perhaps sense God's presence.

"I feel that God is here with me, meeting me", says Tine A. Klovning (29), exhaling after her sacred dance. She has been dancing to the prelude wearing a white cloak and a green rope around her waist. She has practised for a long time; now she knows the steps. She feels the bass in her legs as she follows the rhythm and performs the movements with precision.

### **Dignity**

The multi-sensory church is remotely located, in the thick forests of Andebu a few miles from Tønsberg, Norway. With its brown stain it hardly stands out from the surrounding spruce forest. However, many experiences are waiting inside for those with limited use of their senses. There is one service each month, often with 70 people attending. "Anyone who wants to may join the procession," says pastor Marco Kanehl.

Lasse Egil Seder (62) is hurrying down the aisle, gesturing to people in the pews who respond quickly. Five men smile proudly as they follow Lasse up to the altar

with the wooden cross. Tine comes up to him and hangs a small cross around his neck. Then they take each other's hands and walk down to the first row. "God loves you, you are valuable. Now we will pray to our Father in Heaven", says Marco Kanehl, using sign language.

His voice is vibrating under us. For someone hearing, there can be many unfamiliar sounds – also from the pews. Some of those who cannot hear, feel their voice and let it out. And that is perfectly OK, even though the pastor is in the middle of his sermon. Here people get to be themselves.

The multi-sensory church is all about dignity, being seen and met as 'the one you are', regardless of your needs and limitations. Some people need more to have equal opportunities.

## **Meeting People**

There are many rooms in our Father's house; now Signo has built another, states the welcome brochure of the nationwide diaconal foundation. In Signo the deaf and deafblind get work, housing, education and varied leisure activities. Most of the users have multiple disabilities.

"I believe God wants to meet people the way we are, where we are. I believe he loves each and every one of us very much. It is important for me to communicate everywhere that we are valuable, that there is future and hope, security and love. I notice that it is important to our users to hear the good news, the gospel", says Marco Kanehl. "If I tell the story of the prodigal son, I see joy spread in their faces when I show the father opening his arms. This is how God is".

The half-hour long service is over, and the pastor has told the story of the Ethiopian official who had an encounter with Jesus. Large illustrations slide across the white wall. So do hymns. When the lyrics to Moon and Sun are shown, one of the men has to stroke the illuminated areas.

"It is important that something is happening. I usually use picture stories and objects. At Easter I brought several crowns of thorns, and people could feel them. The users here are so different, we need to have something each one can pick out and take with them. The sermon has to be short and right to the point. People are direct, and I notice quickly when things don't work. In the worst case they close their eyes".

## **An Old Dream**

The Thomas Church is the result of an old dream, Marco Kanehl explains, marching towards the altar. The idea simmered for a long time before Kirkelig Kulturverksted was given the task of designing it, and two former managers in the construction business raised funds and materials.

## **About the name**

According to Kanehl, "Thomas was the disciple who needed a little more. Although Jesus says: Blessed are those who do not see and still believe, he still lets Thomas feel the wound in his side. This church shall be tactile, to be felt. This congregation

does not need to remain passive. This is about possibilities, not limitations. We try to make it possible so that each one can use his or her full potential. One man gets to be the bell ringer and makes the beats, another leads a prayer, and everyone who wishes can come up and pray the five sign prayer - Stay with us; you love us; keep us in your peace, and then they cross their hands over their hearts, the sign for love. Soft light streams in through narrow skylights, helping those who have residual vision navigate. There are guiding lights along the walls, and a wooden beam to guide the blind safely through the room.

Marco Kanehl has taken his place behind the altar: Here are the organist, the light master and the sign language interpreters.

But where are they? The answer is hidden in the computer equipment on the altar cloth. From here he manages sound, light and words. The soundtrack is church music composed especially for the Thomas Church. The lyrics are recorded and shown on the white wall. The pastor communicates the message in sign language with the grammar of the deaf. Norwegian syntax can be challenging for someone who has never heard sound.

“I try to create a service making use of the senses which are still intact. Smell and taste can be linked to what I wish to communicate. When I preach about Jesus who says that we are the light and salt of the world, I can bring some salt, for example. I must make things visible for those who cannot see”

A deafblind man in a wheelchair gestures to the pastor, he wants to feel the water. A not-quite-steady hand fumbles for the baptismal font, fingers are placed tentatively in the lukewarm water, and then he smiles. The joy spreads to the pastor and the companion.

Lasse Seder proudly shows us the Bible stand he has made in the Signo carpentry workshop. Here the altar and the pulpit were also created based on designs from Kirkelig Kulturverksted, a national provider in religious related culture as arts and music. “Lasse is an expert in repairing lawn mowers; quite a handyman” the pastor says.

The 62-year-old has attended church regularly since the 1950s, when he moved to Andebu. During the church opening in December 2012, Lasse Seder led the procession. The church was completely full; there was room for 120, many had to be turned away.

### **Stations Reflecting God**

The various stations in the church are helpful in attempting to say something about God and the church. So what does the Fellowship tapestry at the entrance say? People have conveyed their names, a prayer, or something significant on strips of cloth in vivid colours. People can stop and feel the knots, pictures, flowers and medallions. A small crown is shining, a contribution from His Majesty the King. A small cross is blinking on another ribbon given by Her Majesty Queen Sonja. Both visited Signo before the church was opened.

“We have pictures that can be felt”, the pastor says as he proceeds to the next station, a green globe with reliefs from Bible stories. “If you run your fingers over the wood, you can feel Christ on the cross with his head bowed”

You can also read Bible texts on signs with Braille. The artwork gives a glimpse of the sacred. Care is the name of the softly formed sculpture of a woman embracing a child. Water is trickling down the smooth stone slab on the wall. The deafblind people can run the palms of their hands over the moist stone and perhaps understand more about the water Jesus is talking about in John 4:14: “But whoever drinks the water I give them will never thirst”. The words are chiselled in blue letters. During the official opening there was a knock on the door of the Thomas Church. A man, born deafblind, wanted to come in. He stood at the door, smelling; the wood was new, the cement hardened. He ran his hands along the walls, felt the sound floor and touched the delicate stone sculpture. He quietly examined each object and formed a picture of the premise. The next day the man stood outside again and was guided inside. This time he was not silent. As soon as he crossed the threshold, he jumped high.

“This is what we want for everyone, that they come to the church and are uplifted and happy”, the pastor said.

## **Seeing the World**

Marco Kanehl talks about the amount of information we receive through our senses. “The healthy have learned to filter out only what they need. Sound is more confusing when your hearing is limited. Someone who is hard of hearing does not have the same auditory experience as someone with normal hearing, even if he gets technical help. But the sound floor helps: A deaf lady who came here asked to hear the postlude again because the music touched her. It is obvious that the sound in this church communicates something.”

The pastor distinguishes between those who have become deafblind (acquired) and those who are born deafblind (congenital). “The first group knows what the world looks like. The other group has an entirely different perception of the world. For them the world becomes concrete. They distinguish between warm and cold, soft and hard, pleasant and unpleasant to touch. When we send out vibrations in the church, a deafblind person will notice it even more than someone who has all senses intact”, says Marco Kanehl.

It is now time for solid replenishment and the church coffee is popular! The Thomas café is always crowded. Chocolate cake and buns are on the tables, and the congregation empties the cake stands. Those who need it, get help to consume the buns.

“The social aspect is important. People should be able to enjoy themselves and bring the joy from the service into their everyday lives”, says Kanehl as he prepares for another guided tour.

Busloads of congregations, health associations and cultural groups find their way to Andebu. The developmental disabled from other institutions also arrive. They enjoy the service format, which is easy to understand. Others want to know more.

Professionals from Denmark have studied the church, suggesting there will be more tactile church rooms in that country.

Tine A. Klovning hangs her cloak in the wardrobe. She did not hear the cheerful jazz during the postlude, but she felt the beat and used her entire body in her final dance. In the aisle and side wings she gave glory to God. “It felt good to run, lift my hands and point to heaven. It is good to have a multi-sensory church. It is easier to understand what is happening here than in other churches”, says the 29-year-old.

<sup>1</sup> Originally written in Norwegian and published in Krigsropet (War Cry), Number 36, 2013. Permission was given to translate and publish in Dbl Review

<sup>2</sup> [www.signo.no](http://www.signo.no). The Foundation Signo provides services to deafblind

and deaf people who ask for them, on their terms and based on Christian and humanistic values.

<sup>3</sup> [www.kkv.no/en/English1/Kontakt-info1/](http://www.kkv.no/en/English1/Kontakt-info1/)

## **Alexander leads the way**

**Bettina Kastrup Pedersen**

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At the School at Kastelsvej, 16-year-old Alexander and his team have been using haptic communication during the past year. After five months, the first results are already appearing.

Alexander is a young man of 16 years of age. He is deaf and considered to be functionally blind. He lives at home with his parents and attends school in Kastelsvej<sup>2</sup> (Copenhagen) each day.

Alexander was born with a severe hearing loss and diagnosed with autism at an early age.

At around the age of 7 he was affected by a coma for a period of about five weeks.

He was subsequently diagnosed with the rare condition Acute Inflammatory Demyelinating Polyradiculopathy (AIDP) or Guillain Barré syndrome<sup>3</sup>, a disorder in which the body's immune system attacks part of the peripheral nervous system.

After this trauma, his vision which had been previously considered normal, gradually deteriorated, presumedly as a result of the Guillain Barré syndrome . His walking ability, as well as the fine motor movements with his fingers, were also affected over time as a result of this condition.

Alexander has been able to understand visual sign language for some time.

Recently, as part of his communication development at school, a Deafblind

Consultant introduced tactile sign language to Alexander and his team. This has now become a natural part of communicating with Alexander.

The team around Alexander is very focused on his interests. They spend most of the time helping Alexander to experience the world around him. They spend a lot of time in nature, especially in the forest, where many types of trees are studied. Alexander has developed an impressive knowledge about these trees.

My connection to Alexander is as an educational consultant. Together with his teachers, I was curious if Alexander would gain advantage from using haptic communication. Alexander's interest in his surroundings and the visual memories he appears to retain from his childhood, made us believe that it was possible.

Furthermore the team was very interested in finding a complement to tactile sign language. It was becoming very difficult to communicate with Alexander in that way while outdoors when he was sitting in a wheelchair or on a tandem bike.

At first, we agreed on testing the idea by giving Alexander information about familiar surroundings. This was achieved by drawing on his back; always preceded by the introduction: "now I am going to draw on your back".

### **Things really took off after five months**

In the year that has passed since we started using haptic communication, the team has worked on telling Alexander which way to go when they are out on trips. They also mark the places to stop along the way, as well as drawing special features of the route on Alexander's back.

It is not only on trips out of the house that the teachers communicate with Alexander through the use of touch. They also describe how a room looks, who is inside the room and where people and things are located in relation to him.

It took about five months before Alexander understood how he could use this form of communication. He then began to ask for the proper sign to be placed in a specific location to know where was located.

Alexander has not been able to express himself what he has gained from this added method of communicating. But the team believes that this haptic method has allowed him, through touch, to re-connect with the visual memories of his surroundings. There is no doubt that Alexander 'leads the way'.

### **A relationship based on trust and understanding**

The next focus for Alexander as we continue this program long term will be to use haptics in various social relations to describe moods, facial expressions, and in particular to allow Alexander to recognize who is sitting next to him during lunch in the canteen. Alexander's parents will now be more actively involved in the project and will start communicating in this way at home.

I have no doubt that using haptic communication is a very successful method to describe the surroundings to Alexander and others like him with limited eyesight and hearing. At the same time, it is very important to be very specific about what and when we use this communication method. Professionals need to understand how



this method achieves the best results for these individuals. This can only be accomplished through repeatedly linking the situation with the haptic information provided.

What is crucial to make this haptic method successful is to establish a relationship between the congenitally deafblind person and his/her communication partner that is based on trust and understanding the deafblind person's interests. The professional possessing an excellent ability in the use of tactile communication is paramount.

This above article about Alexander and his introduction to haptic communication was originally featured in the magazine Døvblinde NYT, published by The Danish Resource Centre on Congenital Deafblindness (today a division of the National Resource Centre on Disability, Assistive Technology & Social Psychiatry<sup>4</sup>) at the end of 2010. The original publication of this paper led to the recent production of a booklet Haptiske Signaler<sup>5</sup> (Haptic Signals) about the process Alexander and his team have been through since the start back in 2009.

Even though three years have passed since the original article, this subject has never been more relevant than now. It has turned out that it takes time to get this approach implemented in the various educational environments. And now, in Denmark and the other Scandinavian countries, there is widespread agreement that this is a really important approach to tactile communication.

Today, Alexander tells his parents that haptic signals are an asset to him. Haptic signals are being used as a natural complement to tactile sign language for Alexander.

<sup>1</sup> [www.cdh.rn.dk](http://www.cdh.rn.dk)

<sup>2</sup> Since the article was written in 2010, Alexander is in a new school called Langelinjeskolen.

<sup>3</sup> [www.ninds.gov/disorders/gbs](http://www.ninds.gov/disorders/gbs)

<sup>4</sup> [www.dovblindfodt.dk](http://www.dovblindfodt.dk)

<sup>5</sup> [www.matcen.dk](http://www.matcen.dk)

## **A bridge to the outside world**

**Haptic communication may contribute to giving a better understanding of the outside world to congenitally deafblind people. This relatively new way of communicating actually has a social dimension which other tactile forms of communication may have difficulty in conveying.**

**By Bettina Kastrup Pedersen,  
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People with combined vision and hearing loss are affected with regard to communication, orientation and acquisition of information. This has consequences for social relations, as well as letting the person easily lose track of the surrounding

environment. The ability to capture moods and linguistic aspects of communication are also affected.

Within the field of acquired deafblindness, there has been ongoing work for several years on a form of communication where a partner can communicate moods and give fast information on what is happening around the deafblind person. It is called haptic communication and the experience so far is very positive. People with acquired deafblindness express that it provides security, clarity, courage to explore the environment, and that haptic communication makes them active participants in social relations. These positive comments should give an inspiration to try to transfer these haptic principles to congenitally deafblind people.

### **A part of the tactile family**

Haptic communication is generally about using touch in communication. It is a tool that can contribute to reducing the number of misunderstandings and fill some of the gaps that easily occur when one does not understand things fully through vision and hearing.

While there is very little documented about haptic communication, it is an area of rapid development. Most of the existing publications are written by Lahtinen and Palmer<sup>2</sup>. However, in recent years, there has been more published through small projects undertaken in the Nordic countries.

Since 2009, when we started the project around Alexander (see the article Alexander leads the way in this edition of Dbl Review), the interest in this way of communicating has changed dramatically. The professionals who work with the congenitally deafblind have seen the potential that this method gives to map out the environment, give understanding to the social context, and how it can support language development. It is becoming increasingly clear that the use of haptic communication is an integral part of tactile communication. Haptic communication has now become part of the curriculum for the basic education of professionals in Denmark who work with the congenitally deafblind.

### **Spreading interactive practices**

'Haptic' is derived from the Greek word 'haptikos' which is related to the sense of touch. Haptic is lexically equal to the Latin word 'taktil'. When speaking of communication in connection with deafblind people, the term tactile is connected to tactile communication of language information, (primarily tactile sign language) and other tactile communication methods such as the tactile manual alphabet (international manual alphabet) and the use of uppercase letters drawn on the back of the hand, shoulder or back.

The haptic part may be included in communication in various ways, but is actually not a language like tactile, visual or oral. It is a more open approach to interacting with one's environment and sharing the information with another person. It may, however, contain elements of spoken or sign language.

From a linguistic point of view, haptic communication is about what lies beyond conventional and cultural languages. It is the communication of other forms of expression given to each other, e.g. by signs, facial expression and body language, part of what is traditionally referred to as total communication.

### **Who, what and when**

Within pedagogical approaches to teaching deafblind people, there has been a tradition of developing communication from a point of view of total communication. Tactile/haptic communication may be an additional step towards this philosophy. The various forms of tactile communication can be described as follows:

- Tactile sign language is a language where the deafblind person feels the execution of conventional signs with his hands and on the body.
- Tactile orientation is about a deafblind person feeling his way with the hands in order to get an impression of forms and boundaries in the environment (e.g. finding one's way from one room to another).
- Haptic communication deals with a much more nuanced understanding of touch. Here, the deafblind person has the opportunity to, through another person's touch/movement, perceive form and contour. It expresses the opposite of 'what can be perceived by vision'. For instance, it could be 'drawing' the landscape or the environment on the back of the deafblind person to give the deafblind person an impression of their environment.
- Haptic signals represent a tactile sign/touch system, which can operate in conjunction with the "spoken word".

The interesting thing about haptic communication used with congenitally deafblind people is its ability to create 'a bridge to their outside world'. In other words it is method to provide information about who or what is around the person (i.e. to describe their outside world), allowing them to feel they are part of a larger world. This process of stimulation, which leads to improving their attention and concentration, is believed to improve these individual's cognitive development and social competency.

### **How to begin**

It is not a new thought to consider the term 'haptic' as an integral part of tactile communication. In fact with tactile communication there are already many haptic signals in use; it is just a question of having them documented and developed further. Perhaps it is also a matter of daring to use a lot more 'body focussed signs'. Using haptic signals/haptic communication, as part of tactile communication for congenitally deafblind person will create an expanded social dimension for these individuals by making them feel an important part of a relationship and more broadly, a community. This continues to be one of the largest issues in communication for congenital deafblind people.

<sup>1</sup> www.cdh.rn.dk

<sup>2</sup> Lahtinen and Palmer – co-leaders, Dbl Social-Haptic Communication Network

## **Spectacular Sydney welcomes the world**

### **to the 9th Australian National Deafblind Conference**

In Sydney Australia, on 6-8 June 2014 the 9th National Deafblind Conference - Access to my World, will be held at the Mercure Central Hotel. This Conference is being hosted by Forsight Australia<sup>1</sup>, in conjunction with Australia Deafblind Council (ADBC)<sup>2</sup> and DeafBlind Association (NSW) Inc<sup>3</sup>.

Following the conference, the organizers have planned a social day which includes a tour of Sydney on Monday 9 June.

If you are thinking of visiting Sydney, Australia, come and join us for this special event. The Mercure Central Hotel is located in the Central Business District in close proximity to Central Station and the airport train link.

Who should attend? This Conference will provide a unique opportunity for people who are deafblind, Interpreters, Service Providers, Educators, Carers, Advocates and Families to focus on a wide range of themes within an environment of Disability Reform, Person-centred Planning and the new National Disability Insurance Scheme.

Who should present? This Conference will welcome anyone who fits into the categories above to present on the following topics relating to people with dual sensory loss:

- Advocacy, Self-advocacy and Empowerment
- Dynamic Assessment and Person-centred Planning
- Communication, Social Support and Augmentative and Alternative Communication (AAC)
- Assistive Technology, IT and Social Media
- Accommodation, Day Programs, Therapies, Respite and Drop-in Support
- Community Access, Recreation and Orientation & Mobility
- Education, Adult Learning and Supported Employment

Where to submit your Abstract? To obtain Conference Submission Guidelines, Call for papers, timeframe and Submission forms, please visit the conference website: <http://www.aomevents.com/deafblind2014>. Abstracts are to be submitted no later than Tuesday 28 January 2014.

For more information about the Conference including accommodation options, visit the Forsight Australia website ([www.forsightfoundation.org.au](http://www.forsightfoundation.org.au), click on Conference) or Twitter at <https://twitter.com/ForsightAus>.

<sup>1</sup> [www.forsightfoundation.org.au](http://www.forsightfoundation.org.au)

<sup>2</sup> [www.deafblind.org.au](http://www.deafblind.org.au)

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

<sup>4</sup> [www.mercuresydney.com.au](http://www.mercuresydney.com.au)

## **Grupo Brasil organized another great International Forum**

Grupo Brasil of the Deafblind and MultiSensory Impaired celebrated the Brazilian National Week of Deafblindness and the State and Municipal Day of the Person with Deafblindness, by hosting the successful 5th International Forum on Deafblindness and Multiple Disabilities, the 7th National Meeting of Families and Professionals specializing in Deafblindness and the 8th National Meeting of Deafblind People, at the Federal University of Sao Carlos in Sao Carlos (Sao Paulo State), Brazil, November 21-23, 2013. The theme of this joint event was 'Holding Hands: Assistive Technology, Health and Education for the Inclusion of People with Deafblindness and People with Multiple Disabilities'.

A total of 180 participants and speakers were in attendance from Argentina, Brazil, Canada, Norway, Scotland and USA.

The Forum opened on the evening of November 21 with addresses from various dignitaries representing the city of Sao Carlos, the host University, AHIMSA (the educational organization in São Paulo), ABRAPASCEM (the family association) and ABRASC (the organization representing deafblind individuals). This was followed by the keynote speaker Dr. Tim Hartshorne, Professor of Psychology (Central Michigan University) and noted expert on CHARGE Syndrome who spoke about the needs of the person with CHARGE Syndrome.

The remainder of the three day event was organized around simultaneous Mini Courses, Round Tables, poster sessions and Special Meetings. Each of the sessions together were cleverly designed and successfully satisfied the broad 'Holding Hands' theme.

For Holding Hands, there were presentations on Networks functioning to support people with deafblindness internationally (DbI), Nationally (Canada) and Brazil (Grupo Brasil); for Assistive Technology, Steve Collins from Gallaudet University (USA) spoke about Interpretation and Guide-Interpretations; for Health, there was the keynote speech on CHARGE, Jude Nicholas's presentation on Cognition and Language; for Education, there were presentations on Specialized Educational Services in Brazil, Co-teaching, Tactile Communication, Inclusive Education, Outdoor Activities, importance of families; Inclusion, while being the overall goal, was specifically addressed in presentations on transitions to adult life, importance of collaborative teams, rights of the person with disabilities, social inclusion and participation, identity and self-autonomy, etc. There was also a session that

discussed research carried out in Brazil; an issue which is becoming more and more significant.

According to Vula Ikinomides, this was the first time that Grupo Brasil organized this forum in partnership with a Federal university. The organizers also received support from two government agencies to bring the various international speakers to this event, who included Tim Hartshorne, Steve Collins, Jude Nicholas, Maria Bove, Stan Munroe and Joe Gibson.

According to Vula, More parents of deafblind individuals attended this forum and became new members of ABRAPASCEM. Deafblind individuals were happy to interact more among themselves since they all live in different states of Brazil. Those Brazilians in attendance, professionals, parents and deafblind individuals represented many different states in Brazil, including such cities of Manaus, Cuiabá, Porto Alegre, Rio de Janeiro, São Paulo, São Carlos, Ji-Paraná, Florianópolis, Campo Grande, Barreiras etc.

Grupo Brasil is to be commended again for their great efforts to network with such a broad collection of individuals and organizations to put together such a well-balanced and informative professional conference. This organization is such a wonderful example of an organization that can do 'so much with so little' to promote and develop deafblind services throughout such a vast and diverse country.

Stan Munroe

Dbl Information Officer

## **The Lega del Filo d'Oro<sup>1</sup> expands its reach across Italy**

**Strong commitment and reliance on the support of volunteers and donors has led to the expansion support services for people with deafblindness and multisensory disabilities across Italy**

The Lega del Filo d'Oro is unique in Italy. For nearly 50 years it has provided highly specialised services for people with deafblindness and multisensory disabilities. 'A golden thread which links the deafblind to the world' is the concept which inspired the Association's name and activities. It was founded in 1964, became a Charity in 1967 and was designated as an Onlus (non-profit organization)<sup>2</sup> in 1998. The Association has its national headquarters located in Osimo (situated in the Marches Region), which is also the location of the National Rehabilitation and Diagnostic Centre.

The National Centre provides global evaluation and early intervention for children under the age of 4, providing such services as education, rehabilitation, medical evaluation, research and library resources. For each client, an individually based plan for rehabilitation and communication is developed. This will allow each

deafblind individual to develop a better relationship with the outside world and achieve for them some measure of dignity and autonomy.

The growing demand for specialized assistance and care encouraged the Lega del Filo d'Oro to share its Osimo experience with the entire country. Consequently the Association has undergone significant development during the last ten years. Following the opening of local offices in Lazio (region of Rome) and in Campania (region of Naples), four other new Centres have opened as a result of strong commitment from many people supported by intense technical and scientific research.

The first of these four new adult based centres opened in 2004 in the commune of Lesmo, in the Lombardy Region. Here a residential Social and Health Centre was built to accommodate 42 deafblind and multisensory impaired adults on a full time basis. In 2007 a residential Social and Health Centre was opened in the commune of Molfetta in the Puglia Region. This facility accommodates 40 adults full time and has spaces for 15 adults on a daily basis. A residential Centre was opened in the commune of Termini Imerese in 2010 to serve adults (24 full time and 8 day care) in the Palermo area of Sicily. The fourth and most recent facility opened in January 2013 in Modena in the Region of Emilia Romagna. This completely new residential Social and Rehabilitation Centre, offers full time places for 24 adults. Together these Centres provide greater opportunities for adults who have difficulty finding appropriate assistance locally.

All these new developments have required an increase in staff, which now numbers 500. The staffing includes educational-rehabilitation assistants, physiotherapists, psychologists, doctors, social workers, administrators and general services staff. The Association also relies on a similar number of volunteers who have been given specialized training. With their help it is possible to organize summer holidays for our users and help them participate in various social, recreational, cultural and sporting events.

### **Other projects**

In 2013, the Lega del Filo d'Oro took on an important challenge and started work on a new, highly specialized Centre at the Osimo site. This new Centre will enable all the specialized services which are at present housed in 15 different buildings to come together under one roof. The best thing to come out of this project will be that the Rehabilitation Centre will be able to increase the number of full time places available to 80 from 56 (a 43% increase) and day care places to 20 from 15 (an increase of 33%). This will reduce the long waiting list and provide spaces specifically designed for individual needs.

In addition, additional new local Centre projects are under consideration to further increase the Association's presence throughout Italy. Like the others, these new facilities will offer greater support to families through integrating their deafblind individuals into local social networks and services.

We are pleased to say that Lega del Filo d'Oro is strongly committed to offering users and their families reliable, high quality services provided by trained qualified staff; up to date information on current research, development and experimentation in the field of deafblindness and multisensory impairment and provide opportunities to participate in European projects.

Support from donors

The Lega del Filo d'Oro Association's activities are only partially financed from public funds. Only with the contribution from private donations, which represent about 70% of the Lega's income, is it possible to guarantee our users the assistance they need and to enlarge and develop the services necessary to serve a greater number of people. Fund-raising is therefore of fundamental importance to the enhanced development of the Lega del Filo d'Oro.

Rossano Bartoli  
General Secretary

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<sup>1</sup> [www.legadelfilodoro.it](http://www.legadelfilodoro.it)

<sup>2</sup> [http://it.wikipedia.org/wiki/Organizzazione\\_non\\_lucrativa\\_di\\_utilità\\_sociale](http://it.wikipedia.org/wiki/Organizzazione_non_lucrativa_di_utilità_sociale)

## **Deafblind Ireland**

### **Kathleen Deasy reports:**

With a focus on families with children with multi-sensory impairment, Deafblind Ireland ran some events for young people and their families this year. In April 2013, we ran a Family Day in conjunction with ChildVision<sup>1</sup> in Dublin, Ireland (an education centre for children with visual impairment). Children with visual impairments and/or multi-sensory impairment and their siblings took part in Arts and Crafts classes while a group session for parents was facilitated by an Educational Psychologist. Lunch was provided, followed by a walk around the impressive sensory garden, petting farm and playground at ChildVision. The afternoon closed with an interactive music session with children and parents.

In addition, Deafblind Ireland invited participants to attend an event that provided the opportunity for Children living with Complex Needs and additional Visual/Hearing Impairments, the opportunity to engage in a one to one Interactive Music session, facilitated by a Senior Music Therapist. Feedback from parents was positive and many expressed an interest for more sessions to take place. (See picture of mother



and child). These sessions were made possible due to funding from a generous donation from Iron Mountain Ltd<sup>2</sup>. Additionally, we are grateful to the Anne Sullivan Centre for the Deafblind<sup>3</sup> in Dublin for the use of a premise.

We have also started to run Communication Strategy Workshops for professionals who work with children with sensory impairment and/or complex needs. The first workshop focused on strategies using Tangible Objects of Reference.

We plan to run the Professional Certificate Course in Multi-sensory Impairment in University College Cork<sup>4</sup> in 2014. Previously, 26 candidates participated in the 2012 Certificate Course in Maynooth, County Kildare.

On a sombre note, we are very sad to announce on September 12th, one of the founding members of Deafblind Ireland, Josie Connolly, passed away. No words can adequately describe the loss that all of us at Deafblind Ireland are experiencing. As a parent of an individual with multi-sensory impairment, her vision for Deafblind Ireland was to offer support and guidance to families affected by this disability. We will miss her immense kindness, patience and gentle strength that guided all of us in this organisation. We express our deepest condolences and sympathy to all her family and friends.

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1 [www.stjosephsvi.ie](http://www.stjosephsvi.ie)

2 [www.ironmountain.com](http://www.ironmountain.com)

3 [www.annesullivan.ie](http://www.annesullivan.ie)

4 [www.ucc.ie/en/ace-hdfids/](http://www.ucc.ie/en/ace-hdfids/)

## **Our deafblind actors are the inspiration!**

**Theatre-group 'Beautiful View' creates the nicest views<sup>1</sup>**

### **About Toneel Mooi Uitzicht (Beautiful View)**

This article is about our theater group 'Toneel Mooi Uitzicht'<sup>2</sup>. It's a Dutch name meaning: Theatre Beautiful View. Toneel Mooi Uitzicht is a part of Kalorama<sup>3</sup> – The Centre for the Deafblind in Beek-Ubbergen, the Netherlands.

My name is Casper Schimmel, professional director and 'theatre-producer'. I'm a graduate from the School of Arts in Arnhem, Netherlands. Shortly after beginning my work at Kalorama in 2010, I formed Toneel Mooi Uitzicht. This group comprises 23 deafblind actors who live at the Kalorama Centre. Each actor brings with them their

own unique talents and qualities. Being a large group, the actors usually work separately in three smaller groups.

### **Different types of Theatre Projects**

Our group provides various performances, which we call supportive theatre, to celebrate special occasions, such as Christmas shows, street fairs, neighbourhood day, etc.

Once a year, the group performs a large theatre production, completely written and prepared by the group themselves. Our most recent production 'Contact' (May 2013) played to an audience for four nights. Previous productions included: 'Romeo and Juliette' (2011) and 'Kalorama is on a Mountain' (2012). While the title of the next performance has not been decided, for sure it will be a performance "for all the senses"

Working with deafblind actors is a special challenge as they have different levels of abilities and disabilities. A great deal of communication assistance is required from staff assistants and interpreters to help with the interactions during the rehearsals and performances.

Since we began the theatre, a great deal of understanding and growth has developed among the performers through the focus on communication interactions during the preparation, rehearsals and performances.

### **Making theatre - it's all improvisation!**

The method we use to make theater is improvisation! When we start, there is no script. We write the texts then create our own scenes and props. We then think about how to combine them together in the program which includes many different scenes to fit with the theme.

When we chose our recent theme Contact, we decided it would be a Theatre on Location Project. The performances would be done on location throughout the premises of Kalorama and different scenic locations throughout the village of Beek-Ubbergen.

The performance started with a scene first in the Kalorama theatre, with the audience present. Following this first scene, the audience was split up in three groups and followed an attendant from location to location where they were entertained by a different actor-group performance. The final scene of the show occurred in the parking lot area where the travelling audience came together with all the actors for one final performance based on the same theme. In this way the actors successfully worked separately and together!

### **The actors are the inspiration**

As the director, the most important thing for me is the role the actors play throughout the entire process. Their individual ideas and skills to create the performance are indeed an inspiration!

### **I give you three examples of my inspiration:**

First example features one man who has lived for over 30 of his 50 years at the Kalorama Centre. As well as being cognitively impaired, his visual and hearing abilities are declining, limiting his independence. When acting he demonstrates a good understanding of such emotions as happiness, sadness, anger, and fear. He has difficulty acting such nuanced emotions as jealousy and disappointment. It seems difficult for him to understand the difference between reality and theatre. At the same time he is very funny and has good dancing moves. Because I have known him for some time, I chose for him a scene I knew he could understand well. I let him play a slapstick scene using anger and sadness, knowing that being nice in the scene was not real to him. Last year he played in a scene where he cheerfully danced, slept and snored and then woke up to scare the dog. He liked to perform this scene very much. He asked me after each rehearsal whether he played the scene well. He gives the right information for me to choose the perfect things for his scenes. I was successful to make 'tailor-made' scenes for both his performances.

Second example is a woman with acquired deafblindness. She has become more dependent and passive since the recent onset of her disability robbed her of her former rich and fulfilling life. It was difficult to motivate her initially with theater. She thought playing theater is a bit crazy and not real. Slapstick was not her piece of cake. It was difficult to challenge her to play theater until I realized that if I gave her a familiar not 'crazy' role that she understood, it might inspire her. So when I grabbed the baby doll in the rehearsal room and indicated that the child had to be comforted by her, the 'mother in her' instantly connected with this role! She played her scene extremely well, experiencing all the emotions in caring for her child. She enjoyed the applause and good reviews after the performance!

The last example I give is about a woman who is very intelligent and had worked in a hospital some years ago as a manager. She has acquired deafblindness and is unable to walk. While her severe sensory disabilities restrict her acting possibilities, it has not limited other important aspects. She has many good ideas and can write beautiful theatre scripts. Unfortunately her speech is difficult to understand so the theatre group benefits largely from her writing abilities. But she continues to act in the performances, using body language interpreted to the audience by an attendant.

Most of the actors know very well what parts they would like to play in each performance. If the actor does not know initially what to play, I improvise for them using different emotions, costumes and/or props. Following that I make observations and soon enough I know which role best suits the individual. I lead and guide the actors, and am constantly inspired by them.

It is important to say that nothing in my role as director is clear-cut. I have to keep my mind, ears and eyes wide open and flexible. I work within the reality of current circumstances, working with these physically vulnerable people. At the last moment it could happen that one of the actors can't play anymore in our performance. Then we must improvise and make it possible to have other actors and attendants

participate in the performance. We must change when the circumstances demand that. That's our method. The actors are the main thing, and they play their part in their best way possible. We create short stories and we come together to make beautiful scenes and performances.

Casper Schimmel

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### **Words from Actor/Writer – Peter Modderman**

I cannot see very well. Where are the trees?  
And where are the birds?  
What shall I do?  
I feel angry.  
I cannot see the beautiful women.  
I am exhausted (It is over)  
I'm leaving! (I quit).  
Is there somebody who can cheer me up?  
I feel sad.  
Smelling, that is the only thing I can do.  
But looking around, no!  
What else?  
Who wants to touch me?  
My skin; my face.  
I did it wrong. Again and again,  
I try to do my best, I try to stand up for myself.  
Is it possible?

Yes, it is!  
There is just one thing:  
I should not be afraid to fail!  
I think for myself: keep calm, buddy.  
Stop making yourself crazy.  
Is it possible?  
Oh yes!  
You only live once!

### **Actress/Writer – Marianne Roosen**

It starts with eye contact,  
then follows the look of understanding.  
I can't do it anymore.  
I must do it by talking, listening, feeling.

And how can you do it?  
How do you contact me?  
Not by shouting,  
since I cannot really stand it.  
Tell peacefully who you are  
and then we really make contact!

<sup>1</sup> Part of the theatre group participated in a Focus Group during the 8th DbI European Conference, Lille France, August 26, 2013

<sup>2</sup> [www.everyoneweb.com/mooiuitzicht](http://www.everyoneweb.com/mooiuitzicht)

<sup>3</sup> [www.kalorama.nl](http://www.kalorama.nl)

## **New book ‘Congenital Deafblindness’ published by Bartiméus**

Saskia Damen and Mijkje Worm, Psychologists from the Bartiméus Expertise Centre for Deafblindness<sup>1</sup> in the Netherlands, recently co-authored a book titled Congenital Deafblindness<sup>2</sup>.

### **Reason for this publication**

Mijkje and Saskia decided to write this book because of their impressions about the general lack of expert knowledge possessed by many people who are in charge of the daily support of individuals with congenital deafblindness. According to the authors, they believe there continues to be a serious lack of understanding about these individuals with sensory disabilities inside and outside the Netherlands. As a result, many of these individuals are not given the appropriate support which can lead to severe developmental delay, behavioural problems and social isolation. This is supported by research<sup>3</sup> suggesting that many individuals with sensory disabilities are often not identified.

Through this book, the authors are offering both technical and practical information to parents, caregivers, teachers and professionals involved in supporting people with congenital deafblindness. As psychologists, Mijkje and Saskia report first-hand evidence of how people with congenital deafblindness flourish with the correct support. In fact, these individuals often exhibit more capabilities than their family members expected of them. They report other scientific research that supports their practical experience that the quality of life of people with visual and hearing disabilities can be significantly improved with proper individualized support, including modifying their social and physical environment.

## **Content of the book**

The first section of the book provides technical background information about congenital deafblindness. It includes discussion about the various causes, the characteristics of the four subgroupings of this classification of deafblindness, medical and psychosocial assessment, the impact of congenital deafblindness on the individual's education and social development, including the individual's various communication options.

The second part of the book provides insight into the daily functioning of people with congenital deafblindness. A number of topics are addressed including: physical and psychological wellbeing, interaction and communication abilities, processing information and acquiring knowledge, orientation and mobility, etc. Topics are illustrated by case-examples and photographs.

The third section of the book describes how the physical and social environment can be adapted to fit the lifelong support needs of people with congenital deafblindness. This section includes discussions about housing and daily activities, special aids and the role of the caregiver. A listing of relevant literature completes the book.

## **Summary and Acknowledgements**

In summary, this book represents a description of knowledge about congenital deafblindness that the authors acquired while working as psychologists for an organization that provides specialized services for people with deafblindness. During the preparation of this book the authors collaborated with people who were deafblind and colleagues in the field, both nationally and internationally.

The authors want to thank the Bartiméus Sonneheerdt Foundation for their financial support of this publication<sup>4</sup>. They also want to thank the clients of Bartiméus and their relatives for allowing photos to be taken by photographer Ingrid Korenstra. Furthermore they thank the members of the reading committee, from the Dutch network of people with deafblindness, Bartiméus, Royal Dutch Kentalis, Royal Visio and the University of Groningen.

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<sup>1</sup> [www.bartimeus.nl](http://www.bartimeus.nl)

<sup>2</sup> Damen, S. & Worm, M. Congenital Deafblindness (2013). Bartiméus: Doorn, The Netherlands

<sup>3</sup> Fellingner, J., Holzinger, D., Dirmhirn, A., van Dijk, J. & Goldberg, D. (2009). Failure to detect deaf-blindness in a population of people with intellectual disability. Journal of Intellectual Disability Research: JIDR, 53(10), 874-881

<sup>4</sup> The book can be ordered at the Bartimeus website  
[http://www.bartimeus.nl/publicaties\\_shop\\_product/84152](http://www.bartimeus.nl/publicaties_shop_product/84152)

## **Sense International Romania opens two additional vocational workshops October, 2013**

Sense International (Romania) has embarked on a new journey, developing vocational services for deafblind/multisensory impaired children and young people. This initiative complements the two existing programmes developed in Romania: early intervention for newborn babies and education services for deafblind/MSI children in school.

Responding to concerns from parents and teachers regarding the future of their children after leaving the education system, SI(R) has initiated a vocational programme called A Sense for Life in three major cities in Romania: Bucharest, Galați and Iași. With the financial support from Orange Foundation, SI(R) has developed strategic partnerships with local authorities in each of the three towns, with the purpose of increasing the chances of an independent life and social integration of deafblind/MSI young people.

After having officially launched a Mini-typography vocational centre in Bucharest in May 2013, two more vocational centres were opened in October 2013.

On October 8, deafblind/MSI (multisensory impaired) young people, their families, local authorities and teachers all got together to celebrate the launch of a new and interesting element in the Vocational Special School “Paul Popescu Neveanu” from Galați. Beginning with this school year, a group of young deafblind people have the opportunity to learn and apply horticulture skills in their “Little Gardener” Greenhouse.

“It is an opportunity for them to learn a trade for a better future”, says Dumitru Bălașa, the father of a young man eager to learn all the tricks of the trade. With the support of the local partners, Galați County Council and Galați School Inspectorate, we hope this greenhouse will be a perfect environment for deafblind youth to learn the skills and then find a job in the field.

On October 18, the third vocational centre, a Marzipan Molding Laboratory, was launched in Iași. Developed in partnership with the Special Vocational Special School “Vasile Pavelcu” from Iași, the laboratory is intended to give deafblind/MSI young students the practical skills of molding marzipan and decorating cakes. It is both a pleasant trade, and a useful set of skills, for the students, as they will have increased chances for finding a job after graduation.

The event was attended by deafblind/MSI young people, their families, teachers and local authorities – partners in the project. “What happens today is a unique chance for young adults with deafblindness to learn and practice new skills in a safe environment, which will increase their self-esteem as well as pave the way towards their future employment”, says Carmen Gavrilă, Lasi General School Inspector.

The project A Sense for Life intends to increase the chances for deafblind/MSI young people from Bucharest, Galati and Lasi to learn a trade that will ensure their professional and social integration upon graduation. The children and young people with multiple sensory disabilities had the opportunity to meet each other in September, by spending three wonderful days in ARTED camp from Durău, a mountain resort in the Eastern part of Romania. Accompanied by teachers, parents

and even grandparents, they breathed the fresh air of Ceahlău mountains and had unique and memorable experiences: from high-wire crossing to wall climbing and from trips to games and dances. It was an unforgettable and unique experience for all of them, most of them being out of their home town for the first time in their life. SI(R) will support the implementation of the projects (the mini-typography, the greenhouse and the laboratory for marzipan molding), actively involving local authorities and making them responsible for the sustainability of the project in the future.

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## **An Exceptional Fellow:**

### **A Father's Story<sup>1</sup>**

The following represents extracts from Svein Olav Kolset's plenary presentation during the 8th Dbl European Conference, August, 2013, Lille France.

#### **Why does a father write?**

- Parents carry the history of their children and they cannot tell their story themselves.
- To illustrate a life lived and fought for outside the spotlight.
- To advocate their cause since we must lift them out of oblivion
- To bring to light the many everyday heroes who work with our children

Our children are heroes and they are indeed exceptional!

Torgeir was born in Oslo, Norway, May 1975. He was in poor health after birth and kept in an incubator for two months. He was tube fed for almost two years. He was initially given the diagnosis of Goldenhaar syndrome<sup>2</sup>.

In 1989-90 our family lived in San Diego, California. By coincidence we came in contact with an expert on Goldenhaar syndrome. Consequently, Torgeir then got his second and current diagnosis: CHARGE Syndrome .

CHARGE syndrome: Torgeir's diagnosis at age 14!

C - Coloboma of the eye, central nervous system anomalies

H - Heart defects

A - Atresia of the choanae



R - Retardation of growth and/or development

G - Genital and/or urinary defects

E - Ear anomalies and/or deafness

There are large individual differences among people with CHARGE Syndrome. After our return to Norway we eventually started to work with institutions with expertise in deafblindness to empower Torgeir and to improve his communication skills.

Once the diagnosis was confirmed, as parents we needed to get on to help empower our "exceptional fellow". We focussed on the following measures:

- Seeking various support systems and professionals was of significance to empowering Torgeir.

The long and winding road for Torgeir featured these examples of institutional support:

Ullevål University Hospital (Oslo, Norway)

Voldsløkka kindergarden for hearing impaired (Oslo)

Prestvannet school - Dynamic integration program (Tromsø, Norway)

Kroc Middle School - Hard of hearing class (San Diego, USA)

Nordvoll school for persons with autism (Oslo)

Ragna Ringdal Centre - with counseling from Skådalen Competence Centre (Oslo)

Conrad Svendsen Center - Deaf and Deafblind program (Oslo)

Where would Torgeir be without them?

Examples of Torgeir's professional expertise support through his long and winding road included:

Teachers, Sign language experts, Physiotherapists, Psychologists and Psychiatrists, Medical doctors, Health workers, Nurses, Social workers, Students and Trainees. Hundreds of people have worked and worked with Torgeir!

- Undertaking communication training for ourselves to help Torgeir was another example of working towards his empowerment.
- Exposing Torgeir to a variety of early life experiences was a further example of us as parents enhancing his empowerment.
- Encouraging Torgeir to take part in different physical activities as a means to increase his physical and mental development and overall health.

The importance of being physically active is generally underestimated for our children. Often there is a lack of knowledge among professionals and good understanding of the best practical approaches. In this area we need more success stories.

- Strong family support and interaction is fundamental to Torgeir's empowerment

- Promoting family values and traditions were also important means towards Torgeir's empowerment. It is important for parents and professionals to increase the visibility of our children in all walks of life

- An active formal education program was one of the essentials of Torgeir's empowerment process.

When school ends education must continue

- Last but not least where would Torgeir be without his parents? In Torgeir's life, parent involvement has been a key to his empowerment.

Where is the manual to proceed following diagnosis? What is the roadmap to increased empowerment for individuals like Torgeir and others with CHARGE and other disabilities?

### **I suggest the following:**

- More collaboration among professionals, including doctors, teachers, physical therapists and social workers. This is often outside their "comfort zone" but this collaboration is necessary.
- More research both in pedagogics, special education, pediatrics, technical appliances, web and internet based teaching programs, nutrition, physical activity etc.
- More evidence based work with deafblind people. This means documenting measures that work.
- Learn from success stories! This depends on those stories being disseminated. Show how to improve the individual's mastering of daily life as well as improving their overall quality of life and health.
- More research, more books, videos and more media and internet exposure is needed. Develop a better understanding of medical problems and treatments for growing old as a deafblind person or with CHARGE syndrome. More medical data needed.
- Develop a better understanding of mood disorders, depression, anxiety, 'troublesome behaviour' among the deafblind population.
- Parents need to organize as they are an untapped resource. Parents with special skills or interests can be useful partners to professionals in their work with deafblind persons and those with CHARGE Syndrome.

Everything is possible with commitment, strong will, more knowledge and 'good practice' success stories.

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<sup>1</sup> Published by Dinamo Forlag, Lysaker, Norway, 2011. Copies of An Exceptional Fellow are available from the author.

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# Self-Regulation in Individuals with CHARGE Syndrome

Maria Ramirez<sup>1</sup>, Timothy S. Hartshorne<sup>2</sup> and Jude Nicholas<sup>3</sup>

Everyone has goals. As I (Hartshorne) write this it is Friday late morning, and my mind is wandering to how I might spend my time over the weekend. There is some painting that might be done, certainly gardening, a few newspapers I want to read because I got behind on them, and I should probably plan some time for relaxation and my family. Yes, I have goals, but actually moving towards meeting any of my goals depends heavily on how I regulate myself. I need to focus my mind on what I want to achieve, organize my behaviors around tasks, manage my emotions so that I can experience satisfaction as I move toward completion, and maintain my physical equilibrium and arousal levels.

To use an academic example, suppose a person had an exam to prepare for. Focusing attention and thinking about the material is a cognitive task that requires regulation. Engaging in study behaviors such as sitting at a desk, keeping eyes focused, and staying engaged is a behavior task that requires regulation. Exams often produce feelings such as anxiety or apathy, and managing these emotions so that they do not interfere with focus is an emotion task also needing regulation. Finally, avoiding fatigue, eating well, sleeping, and focusing one's senses are physiological tasks to be regulated.

## What is Self-Regulation?

Nicholas and Hartshorne (2009) have proposed four dimensions of self-regulation: cognition, behavior, emotion, and physiology. Self-regulation may be defined as the capacity to manage one's own thoughts, actions, feelings and physiological states in adaptive and flexible ways across a range of contexts. Both internal and external processes are involved in self-regulation. In order to describe regulation as 'self-regulation', two components are necessary: 1) self-awareness of the process and 2) a subsequent goal-directed action. Self-regulation begins with a goal, and that goal describes what you want to have happen and what you must do to make that goal happen. Self-regulation involves gauging internal and external forms of information and responding appropriately under environmental expectations. This feedback-control is important in tracking progress towards a goal (Schmeichel & Baumeister, 2004).

## Development of Self-Regulation

Infants begin to regulate arousal and sensorimotor responses even before birth (Florez, 2011). DeGangi (2000) provides a framework for understanding the developmental progression of self-regulation. One of the first steps toward the

development of self-regulation is the infant's emerging capacity to attain a level of homeostasis while at the same time exploring his or her environment and regulating arousal and response to stimulation. The development of the mechanisms underlying self-regulation is believed to be the product of the interplay between physiological maturation, caregiver responsiveness, and the child's adaptation to demands posed by the environment (Lyons-Ruth & Zeanah, 1993.; Rothbart & Derryberry, 1981). Other steps that comprise the development of self-regulation include the child's ability 1) to modulate and process sensory experiences, 2) to coordinate simple motor actions, intentionality, reciprocal interactions, and organized effects, and 3) to display self-control, create mental images, pretend play, and use language functionally.

According to Florez (2011) toddlers start inhibiting responses and complying with caregivers at an early age. By age four, children begin to exhibit more complex forms of self-regulation, such as anticipating and modifying appropriate responses. Self-regulation skills develop gradually as children learn strategies to manage incoming information, choose appropriate responses, and maintain levels of arousal that will allow them to actively participate in learning.

To develop self-regulation skills, children need many opportunities to experience and practice with adults and peers (Florez, 2011). Dysregulation is the inability to properly exhibit, inhibit, and alter thoughts, emotions, physiology and behavior (DeGangi, 2000). This inability often results in problems with sleep, feeding, attention, and sensory processing. These problems may later escalate to challenging behavior, and deficits in attention and inhibition.

### Dimensions of self-regulation

Self-regulation of physiology refers to the ability one has to alter one's own states and responses to meet the needs of the body. This form of regulation is under the control of the somatic, endocrine, and autonomic nervous systems, but is accessible to self-control. An integral aspect of physiological self-regulation is the regulation of sensory systems, including sensory integration, or the ability to process and integrate sensory information (Schaaf & Miller, 2005). According to Kuypers (2011) sensory integration plays a pivotal role in the process and integration of self-regulatory processes. Difficulties in sensory processing may lead to difficulties in social, cognitive, and sensorimotor development (Dunn, 1997).

Self-regulation of behavior is having an awareness of a behavior and choosing those behaviors most adaptive toward achieving a goal. Behavior self-regulation was defined by Jahromi and Stifter (2008) as goal directed and purposeful behavioral patterns consisting of one's ability to inhibit activity, regulate pace of movement, and delay gratification.

Self-regulation of cognition is voluntarily regulating thoughts and mental processes by balancing inhibition and initiation of behavior in order to achieve a goal. Mental processes involved may include:

- attention
- working memory
- memory

- learning (as well as using prior learning)
- reasoning
- problem-solving
- decision-making
- metacognition
- motivation around goal directedness

Self-regulation of emotion is a process involving the analysis, control, alteration, or prevention of emotional expression and experiences that is adaptive for a situation. This can occur at different times relative to the emotional response. Using emotion regulation, the individual analyzes, controls, alters, or prevents behaviors related to the expression of emotions (Lamm & Lewis, 2010).

### **An Example**

A few days before a scheduled orthodontic surgery, an 11 year old with CHARGE syndrome was reported to have 'behavioral issues' at school. His teachers reported to the parent that he was refusing to do work, was kicking objects, was rude to other children, and was frequently screaming "I am so mad." All behavior is communication, and so it is worthwhile considering what he might be communicating. In this case it seems likely that he was communicating that he was at least very concerned about the surgery. While it would be tempting to describe this boy as failing to self-regulate, it can be seen that his emotions, behavior, thoughts, and physiological state were all nicely constructed to communicate his attitude toward the upcoming surgery (his goal). First, consider the child's emotion regulation. Given the upcoming surgery, it is likely that he was scared, anxious, stressed, and possibly confused. He was able to self-identify his emotion as 'mad'. The child's behaviors were refusing to do work, kicking, screaming and not being nice to his classmates. Although not socially appropriate, they nicely served the goal of communicating his concerns. In addition, he may well have been having difficulty regulating his cognition (problem-solving other ways of expressing his anger, or reduced ability to monitor the problem-solving process due to poor working memory) and physiologically controlling his internal arousal levels. While we have described these as separate self-regulatory systems, in actuality they impact each other. He may be channeling his anxiety, fear, and anger by engaging in these behaviors, which may be his learned way of regulating emotions such as confusion, fear, anxiety and anger. By increasing his anger, he increases his arousal levels. Once aroused it may be difficult to focus his thinking and so he reacts rather than contemplates. It is important to recognize that this is self-regulation, although deficient, and not wanton misbehavior. But his attempts at self-regulation are not sophisticated and need to develop so that he can more effectively communicate and achieve his goals.

## **Self-regulation issues in CHARGE syndrome**

Hartshorne (2011) proposed a behavioral phenotype for CHARGE which includes: “under conditions of stress and sensory overload, find it difficult to self-regulate and easily lose behavioral control” (p. 323). As DeGangi (2000) states, early deficiencies in self-regulation may lead to challenging behavior, and deficits in attention and inhibition. One source of self-regulatory difficulty is likely the presence of multi-sensory impairments, limiting both the child’s exposure to environmental stimuli and exposure to models interacting and reacting to the environment. This limited exposure may delay or inhibit self-regulatory strategies.

A second source of the challenges with self-regulation is executive dysfunction. These are essentially control functions (Diamond, 2012). The constructs of self-regulation and executive function exhibit considerable overlap, and both constructs have been characterized as including cognitive processes, emotional responses, and behavioral impulses (Isquith, Crawford, Espy & Gioia 2005). Executive functions are abilities utilized in monitoring, controlling, and regulating thought and action (Carlson, Davis & Leach, 2005). They include processes that coordinate abilities such as attention and memory, strategic planning, decision making, judgment, self-perception, self-monitoring and both direct and regulated behavior (Nicholas, 2005). Thus, they are very involved in and fundamental to self-regulation. Hartshorne, Nicholas, Grialou & Russ (2007) found that children with CHARGE frequently have deficiencies in executive functions, particularly with shifting from task to task, self-monitoring one’s actions, and inhibiting unwanted thoughts, behaviors, or emotions. Thus, individuals with CHARGE syndrome may have difficulties with using their executive functions for purposes of self-regulation and attaining their goals.

Third, there is emerging literature on self-regulatory strength and depletion (Bauer & Baumeister, 2011). Research indicates that effort expended in maintaining self-control and self-regulation uses up the strength to keep on self-regulating. This suggests that when a child with CHARGE manages to maintain self-control in a stressful situation, they may likely ‘melt down’ if there is another stressful situation soon after. The physical complications of CHARGE syndrome alone may reduce stamina. Maintaining self-control through self-regulation may prove to be extremely challenging for individuals with CHARGE.

Individuals with CHARGE syndrome experience a constellation of challenges that may be contributing factors to the presence of difficulties across the four dimensions of self-regulation. In understanding their ‘dysregulation’, it is important to remember that those behaviors we may perceive as difficult or challenging may in fact be a manifestation of their sensory difficulties, executive dysfunction, and fatigue.

Although some behaviors seem ‘challenging’ to us, they may also be an adaptive way for individuals to interact with their environment. In other words, challenging behavior may be self-regulatory behavior, even if the behaviors may not be perceived as socially acceptable. Our roles as professionals and parents should be that of a bi-directional mediator or a bridge which facilitates the child’s interaction with their environment and provides them with the tools to ‘see’ and ‘be’ themselves within their environment.

In future articles, we will look more closely at the four dimensions of self-regulation in individuals with CHARGE syndrome.

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## **The needs of the person with CHARGE Syndrome**

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CHARGE syndrome can fool you. Because children with CHARGE often exceed all expectations for what they “should” be able to accomplish, the extent of their disabilities can be overlooked. Persons with CHARGE are multisensory impaired. The debilitating effects of this are staggering and hard to even imagine. We take our senses for granted. It is possible to understand that being deaf or being visually impaired would be difficult, but when the combination occurs alongside vestibular, proprioceptive and olfactory deficits, often accompanied by tactile defensiveness, it is hard to imagine how they make sense out of the world. Then throw in things like heart defects, swallowing and breathing difficulties, chronic ear and sinus infections, gastrointestinal pain, and on and on, and suddenly what children with CHARGE accomplish becomes heroic. But far too often these achievements are taken for granted, and people are suddenly shocked when the child is unable to accomplish something, particularly an emotional or behavioral challenge. Even with the wide variability in ability and disability in children with CHARGE it is important to understand that they are dealing with staggering obstacles, and deserve to be given as much allowance and understanding as possible.



In spite of the obstacles they may face, persons with CHARGE can accomplish a great deal, particularly when their needs are met. But it takes imagination, creativity and dedication, to ensure that they are. I will address five basic needs: communication, regulation and regularity, a social world, a functioning support team, and quality of life.

## **Communication**

The ability to communicate is central to life. While everyone communicates, not every form of communication is understood by others. This is the central problem. This paper is in English. That is fine unless you do not read English. So we use a translator. This is the need of many children with CHARGE: someone to translate their experience so that they can communicate. The form of communication (spoken, signed, gestured, etc.) is much less important than the ability of the communicative partner to understand.

Communication must be respected and responded to or it will not be sustained. A girl with CHARGE was having temper tantrums and behavior meltdowns because she did not like to sit in her chair in her classroom for more than about 10 minutes. I had to wonder what the bigger concern was, staying in her chair or avoiding the negative behaviors. I suggested that she be taught a sign for when she wanted to get out of her chair. But if that is not respected, if she is not allowed to get out of her chair after she makes an appropriate request, then there is no reason for her to not revert to the negative behaviors, because they work every time.

My son used to grab my arm and lead me to the bathroom when he wanted a bath. If it was not a convenient time for me, I would sign "no" and lead him away from the bathroom. Very often negative behavior was the result. When my wife suggested that I respect his communication by letting him know that I understood, I let him take me to the bathroom. When I signed "what" he replied by signing "bath." I shook my head and signed "no, bath finished." He walked calmly from the bathroom. He knew that I understood what he wanted, and he understood my response.

Negative behavior, particularly when it is not typical behavior, can mean many different things, and when the problem is identified and dealt with, the person's behavior may improve. But when it is ignored or punished, the behavior can easily escalate. All behavior is communication. Once it is appropriately responded to, the behavior may become less of a problem. And, alternative behaviors can be taught, as long as they are respected.

## **Regulation and Regularity**

I once commuted an hour to work through the countryside and many different villages, leaving every morning at about the same time. In every village the same lights were on or turning on, the same people were coming out of their homes and getting into their cars. I was impressed by the regularity of it all. Life becomes more predictable when it is regular.

A challenge, particularly for those with sensory impairments, is making things regular. One way we do this is through self-regulation, or managing our own thoughts, actions, feelings and physiological states. Self-regulation begins with a goal. Perhaps the goal is getting to work on time. I have to make sure I am awake in time (physiological) to get myself out of bed (behavior), and think about the tasks of the morning and day ahead (cognitive), and maintain an appropriate level of enthusiasm (emotion). Some people find these tasks extremely challenging. We all know some people who cannot get anywhere on time. David Brown and I have proposed that much of the challenging behavior we see in persons with CHARGE reflects attempts to self-regulate and should be understood as such. A child may come home from school after a stressful day of trying to stay in control with all of the challenges of navigating school work and activity, with sensory impairments making understanding difficult. The first thing they do is throw off their glasses and hearing device and have a meltdown. While this does not seem like self-regulation it is. The only way this child knows to relieve the stress is to tantrum until they are exhausted. And it works every time.

We need to deliberately teach how to better self-regulate. What do you do when you have had it and feel like you might lose it? One parent learned to greet her child with CHARGE after school with lit candles, calm music, a cup of tea and a cuddle on the couch. The child learned an alternative method for self-regulation.

Individuals with sensory impairments often live at the mercy of other people's decisions and planning. A child might be enjoying lying on the bed after school, only to be suddenly whisked out to the car, perhaps for a five minute drive for shopping, or a 10 hour drive to visit grandmother. An unpredictable life often results in negative behavior. All people want to be able to make choices, and to know their schedule, and to make life predictable. I was to observe a girl with CHARGE in her classroom during a day where she normally left for a work site. The parents created a social story book for her to read every day for a week before I visited that talked about how on Thursdays Amanda goes to Wal-Mart to work, but that Dr. Tim is coming to visit, and so on this Thursday Amanda is going to stay at school. The day came and Amanda stayed in her seat very happily while some of her fellow students left for Wal-Mart.

## **Social Connection**

Humans are social beings. Children with CHARGE want friends and want to have a typical social life. But their social skills can lag because sensory impairments can make it difficult to understand the social world. They may also feel their appearance makes them different and interferes with friends and dating.

The social life of some adults with disabilities often revolves around family and service providers. After family, the person they see most often may be their physician. In some cases this is addressed by contact with other people with disabilities. There may be job programs where persons with disabilities work together, and social programs so that they can get together, and group homes so that they can also live together. There are even sometimes special religious

programs so that they can worship together. While a social world restricted to others with disabilities may be superior to one of isolation, it is not true community living. It perpetuates a “we” vs. “them” mentality. It is segregation. It is not social inclusion. One method for community inclusion is to build a circle of friends. This means deliberately gathering non-disabled peers who are willing to provide social inclusion. My son with CHARGE has had a circle of friends since kindergarten. Those children in his classroom who seemed most interested in him were invited to join the group, which continued formally into high school, and continues today in that Jacob is known and recognized when he travels around our community. Separating children with CHARGE from their communities means they may never develop the trust that they are important members of those larger communities.

### **Functioning Team**

The mom of a young child with CHARGE: “Tonight I am so very tired of being the person figuring out what’s going on. It’s been awhile since I’ve felt so isolated, scared, on and on. Right now it’s as though nothing is enough to really help. I’m damned tired of this. I would like some help, too. I need it now. My daughter needs it now.” It is extremely difficult to raise a child with CHARGE without a functioning team to provide support, advice, and know-how.

Heart defects, feeding problems, and airway problems can make survival fragile during the first four years. As one parent stated: “How do you know if you have the right doctors and therapists doing the right things and enough of them?” More than one physician is needed due to all of the complicated conditions. Then, how do the parents get the physicians to communicate with each other so that the care can be coordinated? This is not easy, but can be critical to survival.

Once school begins the child has a new team, with specialized teachers and school-based professionals. Some of these people may know a bit about CHARGE, but there is still a problem with coordinating the services so that everyone is on the same page.

A functioning team is one where the members work together, which means they have to meet together. And, the parents need to be a part of this team. What takes place at school and what takes place at home need to be coordinated.

Communication strategies and systems, behavior management, feeding approaches, mobility supports – these are only a few of the systems that need to overlap between home and school.

Over the years we have insisted on monthly team meetings at my son’s school involving the teacher and specialists from the school, his caregivers at home, and us, his parents. This helps to assure that everyone is on the same page, and everyone is trained in the approaches being taken towards Jacob’s development.

### **Quality of Life**

Every human being deserves to have love in their life. Some persons with CHARGE will grow up and get married and sometimes have children. But even when this does

not happen, they still need people who love them. Often this will be parents and siblings, but it can also be others who are involved in their lives. What is essential is to be surrounded by a community of people who love you.

Every human being needs friends. The caregivers who support Jacob frequently take him around town on various excursions. It is a very common occurrence for them to have strangers come up and say “Hi Jacob.” Jacob is known in his community where people care about him. His 10 – 12 caregivers are all about his same age, and so he is always with a peer.

Every human being wants to feel that they contribute to society, and so people take on work. Quality of life can depend on feeling that the work one does deserves and receives dignity and respect. The work should be useful. It should not be work reserved for people with disabilities. That is usually work that is beneath the non-disabled.

Recent research has found that young adults with CHARGE report being fairly healthy, but they have concerns around problems with sleep and with anxiety. Sleep problems are common in CHARGE. Less clear is how to help with this issue. Problems with anxiety can be seen in the obsessive-compulsive behaviors of persons with CHARGE. But again, the best way to address this issue has not been explored.

External factors are also important to quality of life. Housing is a significant issue. Should the young adult continue to live at home, or move into some other kind of arrangement? Transportation can be a concern. Is the young adult able to traverse his or her community? The availability of adult services can be a challenge.

Intervention for vocational issues and the availability of competent medical support are critical.

Every effort should be made to develop a life of quality for every individual. Persons with CHARGE have some unique challenges that must be compensated for, but with planning, and team work, and a community that wants to support them, nothing is impossible.

## **Conclusion**

People who have CHARGE, charge ahead. They tend to be very determined and persistent. That is likely the main reason they learn to walk. By attending to their needs for communication, regularity, community, a functioning team, and quality of life issues, they have amazing potential for living meaningful and fulfilling lives.

## **Network News**

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## **ADBN Network**

### **Liz Duncan reports:**

The Network coordinating group met in October for more planning for the next Conference to be held in Belfast Ireland, November 04-07, 2014.

We met in Belfast so that we could all have a look at the venue and the city, and also meet some of the local planning team from Sense Northern Ireland.

Despite the rain, everyone was impressed by the city and is excited about the forthcoming Conference.

Belfast is a beautiful city, with some lovely buildings, a rich musical history and very friendly people. The city authorities are very supportive of the Conference and we are involving local people in the Conference in lots of different ways, including a competition in a local school to design the logo for the Conference.

The Conference will coincide with the end of a major project across Northern Ireland to develop identification and support of Deafblind people throughout the country.

This has led to a great deal of interest locally in the work of Dbl and the Acquired Deafblindness Network – which is a good example of how the international networks can be useful locally to those outside Dbl.

The Conference programme planning is going well and we will be sending out the call for workshop abstracts in late November 2013, so start putting all those exciting ideas together now in readiness. In response to the feedback from our last Conference in 2012, we have increased the number of workshop spaces we are able to offer, so we really would encourage anyone who is interested to submit an abstract.

The Coordinating Group are also thinking ahead, beyond the Conference in 2014 and are looking for organisations/countries which may be willing to host the next Conference in 2016 (or later). We would be interested to hear from anyone - anywhere – who is interested in working with the Network to host an ADbN event.

Liz Duncan  
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## **CHARGE Network**

### **Andrea Wanka reports:**

The Dbl CHARGE Network met during the time slot allocated on Wednesday August 28th, 2013 during the Dbl European Conference. We hoped that some of the people who were unable to attend the pre-conference on August 24 would participate in the Network session along with those who attended the preconference. In total, 28 participants attended this excellent opportunity to have a face to face meeting of the Network.

After a greeting, the network leaders Andrea Wanka (Germany) and Gail Deuce (UK), gave a short report on the preconference. This was followed by a video from Eva Karlsson (Sweden) featuring a child with CHARGE Syndrome learning to ride her bicycle in her own way and time. Further discussion followed about Eva's presentation and additional topics.

There was a great wish by the professionals in attendance to increase the level of sharing with each other. This led to the decision to use the website [www.dbicharge.org](http://www.dbicharge.org) as the forum for more active in-depth discussions of various topics. There was agreement that the first step would be to discuss further about social-emotional skills, which was one of the main topics during the preconference. Further topics suggested for future discussion included sexuality, sensory integration, behavior, pain, autism, the needs of families from the professionals, etc. The Network Meeting closed with a video of a case study by Andrea Wanka.

For further information or to become a member of the Dbl CHARGE Network please contact [Andrea-Wanka@dbicharge.org](mailto:Andrea-Wanka@dbicharge.org)

## **Communication Network**

### **Anne Nafstad (Norway) and Marlene Daelman (Belgium) report:**

Anne Nafstad (Norway) and Marlene Daelman (Belgium) gave an overview of the activities of the Communication Network over past 25 years, in which they had the pleasure to collaborate from the start with Inger Rodbroe (Denmark), Jacques Souriau (France) and Ton Visser (Netherlands). Later on Marleen Janssen (Netherlands), Flemming Ask Larsen (Denmark) and Paul Hart (Scotland), have joined the Network.

This theoretical overview appeared to be much appreciated by the audience, who didn't really know that the Communication Network had developed so many concepts in such a systematic way.

The second part of this session was organized around a collaborative video-analysis, that worked out well, even in such a big audience. The video discussed was a private one from the Institute KMPI Spermalie (Brugge, Belgium) which showed an interaction between Kevin, a deafblind young man and his partner Carla. The video was chosen as an example of the Network's most recent focus – the Dialogical Self in a Dialogical Space. This analysis was meant as a model of the way the Network had been working during the past years, with its emphasis on empirical based theory. Using the video as an example, their empirical discussions have included: discovering the communicative expressions of people with congenital deafblindness; describing them, categorizing them; discussing their possible meaning and discussing how to relate to them in the role of the communication partner, etc.

In the near future, the Network will be publishing a new document on the basis of this presentation, using this video analysis and other examples to document and explain further their theoretical concepts as discussed briefly above. This is a project in collaboration with Nordens Välfärdscenter (NVC). This will be further discussed at a planned meeting of the Network in February, 2014), at the University of Groningen. The Dbl Communication Network still has many plans, even after 25 years.

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## **Outdoor Network**

### **Joe Gibson reports:**

At the Dbl European Conference in Lille, August 2013, there was a productive meeting with Lucy Drescher the Dbl network co-ordinator. At the network session we looked at a video from the first outdoor week, held in Scotland in 2012. Kari Schjøll Brede from Norway did a presentation about the upcoming Outdoor event planned for late September 2013.

We then had an interesting discussion about the future of the network, including what people wanted from the network; how the network might be able to support people and what people could contribute. Twenty-one new people from five countries signed up to the network during the conference. There are now over 50 individuals on the network list representing the following 16 countries: Austria, Brazil,



Canada, Denmark, England, Finland, Germany, Greece, The Netherlands, Norway, Poland, Scotland, Sweden, Switzerland, USA and Wales.

The importance of the outdoors was featured in the conference on several occasions. Svein Olav Kolset, father of Torgeir, his son with CHARGE syndrome, powerfully encouraged the use of the outdoors in his plenary presentation. Two workshops - "I can do it with my friends" by Kari Schjøll Brede and "Golden Moments" by Inge Mogensen, Karina Højbjerg & Bente Knudsen, both powerfully discussed the use and potential of the outdoors for people with deafblindness.

The second Outdoor Network week was held in Sømådalen, Norway, September 16th- 20th. During the week, participants from Norway, Denmark, England and Scotland got the opportunity, among other things, to travel across a fjord in rowing boats, then hike to a cabin built by two young deafblind men, and spend the night camping out and cooking over a fire. They also experienced catching, cleaning, smoking and then eating fish from the fjord and cooking part of a cow in a fire pit. All these experiences were great starting points for communication with some powerful stories to take home. Everyone had an amazing week and many thanks to Reidar Martin Steigen and all those involved in the planning and running of the week.

If you would like to become part of the Outdoor Network or make contact with people in your country who are part of the network please get in touch with the network coordinator:

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## **Siblings Network**

### **Sabine Kersten reports:**

During the European Conference in Lille I presented<sup>1</sup> a well-attended workshop about the impact of deafblindness on the development of brothers and sisters identity. While not an easy subject to deal with, it is an important one. Deafblindness does not only affect the person who is deafblind; it also affects the family members and significant others in ones' life.

I was born six years after my deafblind brother, into the midst of the whirlwind of our family life. I was my parents' hope. It didn't matter how clever or pretty I was – I was alive and healthy. But despite the unconditional love, the first thing I learned was to be well behaved. Most likely this was my survival instinct. How could my parents have coped with another difficult child? I kept my naughty, needy impulses to myself. Nobody knew that I was often afraid and often chock-full of survivor's guilt.

I could never hurt my parents more than life had hurt them already. So I survived by being good: studying, smiling at my teachers, laughing with my friends. Sometimes I hid myself and cried.

In Africa they say: "You need a whole village to raise a child". They mean to say that the development from childhood to adulthood is not just dependant on the parents. A child learns from his parents, his brothers and sisters, his peers, teachers in school. Processes like social learning and identification influence the relationship between brothers and sisters.

Brothers and sisters influence each other's personality. Different feelings and emotions have a role in this process. Anger is one of the emotions we often see with siblings. Brothers and sisters are not always good companions and behave nice towards each other, even though parents would like that. But anger can be a useful emotion.

Relationships among friends are chosen, among siblings they are a given relationship. If you fight with a friend, you will lose your friend. If you fight with your sibling, you will meet him or her the next day anyway, whether you like it or not. This aspect makes the sibling relationship a good one to learn how to handle conflicts. One can try different strategies and learn which one works best for you.

Here anger can be a useful and constructive emotion, which teaches you how to deal with these situations. But how often are the siblings told that they should not argue with their brother or sister having special needs? But a school-aged boy will be understandably angry if his brother destroys a model car he has been working on for days.

Siblings also have a role in developing each other's conscience!. In early childhood parents will teach their children the good and bad. "you may not hit your sister" or "you may not take a cookie without asking". This way the child's conscience will develop. In adolescence, siblings have a larger role in this than parents do. Parents teach the theory, while siblings and peers will teach the practical side. It is about what is fair, whether it is about trading, divide, teamwork or playing. They will teach you there is more than one truth. Siblings will teach you social skills; skills you will need in your future life. They will tell you all the things you need to know that parents will not always tell you.

Like parents, siblings have a constant need for information. It should be truthful and age appropriate. Even young children need to know what is going on, as they feel a huge responsibility, even at young ages. In "An exceptional fellow", written by Svein Olav Kolset, there is a striking example: The sister (then eight years old) is asked what will happen to her deafblind brother and who will take care of him in the future. Her answer: "it would be better if he died before you do. If you die, you have to tell me what I should do. You have to give me all the orders". She also adds that it is frightening to think about this.

This girl is no exception. I can assure you many siblings feel the responsibility to take care of their deafblind brother or sister, even at very young ages. And that is a heavy burden to carry.

The sibling relationship is the longest lasting family relation we normally endure during our lifespan. Under the best of conditions, this can mean the potential for intimate sharing with a beloved companion throughout one's life. However, when a brother or sister has special needs, it also means an enduring responsibility for the siblings.

Adolescents looking forward to their own lives may feel considerable concern about the future responsibilities they may have for caring for their brother or sister who has a disability. It may effect decisions they make for their own life. Knowing that they will be responsible for their sibling one day can be a big burden. It may prevent siblings to follow their own dreams; develop their own talents. Many siblings worry about the obligations they will have towards their brother or sister in days to come. Every sibling will have to make a choice one day: will I and can I take care of my brother or sister? And how will I arrange all that; how will I find a balance between my own life and the care taking? Parents grow older, and children need to take care of them as well. And if there is only one sibling, the responsibility for your brother or sister with special needs and your parents is a huge one.

There should be support for siblings, including individuals or groups (e.g. "Sibshops") on a need basis. They need to get information and answers to their questions. They need to know they are not the only ones! One sister wrote: "We will become caregivers for our siblings when our parents no longer can. Anyone interested in the welfare of people with disabilities ought to be interested in us."

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<sup>1</sup> Workshop 'A Sisters Identity' presented by Sabine Kerstin at the 8th Dbl European Conference, Lille, France, August 26, 2013

## Rubella Network

### **Joff McGill, the new leader of the Rubella Network reports:**

The Rubella Network featured strongly at the European Conference in Lille. A well-attended workshop on 'Remembering the Past to Understand the Future' cast its eye to history reflecting on the impact rubella has had on individuals, and cast its eye to the future, considering the work still to be done. The issues that emerged from the participants included the experience for individuals with CRS as they age and experience on-going health problems, and the challenges of protecting against rubella and preventing CRS around the world.

Later in the week over 20 people attended a meeting of the Rubella Network. The meeting was an informal chance to meet each other, find out the issues we are all interested in and begin to sketch out some priorities for the network.

Participants included practitioners working with children with CRS, pioneering parents from the early days who are still providing leadership in the field of rare syndromes, a variety of professionals working with adults who are wishing to

generate new knowledge and develop staff skills, and organisations who are working in countries where there is an epidemic of rubella happening every year. Jude Nicholas commented on renewed interest in the life long symptoms of individuals with CRS and the on-going health problems they experience. He reflected that what we are studying and learning about rubella now will be important for other conditions in the future, such as CHARGE, CMV and toxoplasmosis. A number of people were looking for support and knowledge around their work with children, and the meeting reflected that not only were staff across Europe still working with children who have CRS, including in parts of Southern Italy where there have been a number of births in recent years, but that in parts of the world without immunisation (e.g. Africa, parts of Asia), staff and schools and families will be seeking knowledge about how CRS impacts on a person's learning and development.

Led by Henri Faivre the meeting talked about the opportunities that are needed for people with CRS as they age, the services they will require and the health problems they may experience. Building on this then, a number of researchers – including Stan Munroe, Trees van Nunen, Anneke Schoenmaker and Saskia Damen for example, talked about studies done in Canada and Europe that looked at the experience of individuals with CRS and their families. Is it time to re-look at some of this work, update it, or write up data that has continued to be collected.

And participants agreed that Dbl has a role to play in helping people tell the story of rubella and the impact it has on individuals and families, as part of on-going work that is needed throughout the world to strengthen, and in some cases introduce, immunisation programmes. As individuals and organisations around the world we need to lobby for the resources that are needed for the World Health Organisation to meet its goals of reducing and eliminating rubella, and we need to help build the evidence Governments need to commit to immunisation programmes.

Rubella remains a vitally important public health challenge in many parts of the world. In 1961 Peggy Freeman introduced a conference on rubella in the UK with the words 'Prevention must be our aim'. She pioneered much of the work that has followed, and I have no doubt would celebrate the progress we have made, but she would also gently remind us there is much work to be done.

Joff McGill

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# Tactile Communication Network

## Bernadette van den Tillaart reports about the Joint Network Meeting held in Lille during the Dbl European Conference

At the Dbl European conference in Lille, August 2013, the Tactile Communication Network and the Communication Network joined forces to deliver a joint network session. It was kicked off by Paul Hart, representing the Tactile Communication Network, who first gave an overview of the members and the work of the Tactile Communication group in recent years. He then invited the large group of participants to take part in a guided imagery, designed to move people from inhabiting a world where vision and / or hearing might dominate, to a world where touch was their primary source of contact with the external environment.

The long-promised and now recently published film, the Landscape of Touch<sup>1</sup> was presented. This film follows the experience of people - both deafblind and seeing/hearing, as they explore, interact and communicate with each other in the tactile world. The film offers specific images that show the shift in perspective that is required to enter the rich unique world of tactile experience that is inhabited by congenitally deafblind people. It is hoped that the film will lead to enhanced shared understanding between seeing/hearing persons and deafblind persons, and to an increased joyfulness in our mutual exploration of the tactile world in which we all live. The guided imagery is one of the exercises outlined in the companion guide booklet. This booklet is included in the DVD box of 'Landscape of Touch'. There are also other examples of exercises, a few of which were outlined during the discussion that followed the showing of the film. Participants engaged in a lively debate about the learning they could take from the film but also around the power of tactile communication.

References were made also to other publications around tactile communication, including the film 'Traces'<sup>2</sup>, the series of booklets entitled 'Communication and Congenital Deafblindness'<sup>3</sup> and a new book and DVD (in press) from Norway called 'Feel My Language'<sup>4</sup>.

Copies of the Landscape of Touch are available via Sense Scotland's online shop (<http://shop.sensescotland.org.uk/category/67-landscape-of-touch-dvd.aspx>) or Perkins website in their Perkins Products section (<http://www.perkins.org/>).

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<sup>1</sup> Van den Tillaart, B., Vege, G., Miles, B. & Hart, P. (2012). Signo Dovblindesenter (Norway), Perkins International (USA), Sense Scotland

<sup>2</sup> Vege, G., Bjartvik, R.F. & Nafstad, A. (2007). Signo Dovblindesenter, Andebu Norway ([www.signodovblindesenter.no](http://www.signodovblindesenter.no))

<sup>3</sup> Souriau, J., Rodbroe, I. & Janssen, M. (2006-2009)

([www.deafblindinternational.org/network\\_communication.html](http://www.deafblindinternational.org/network_communication.html))

<sup>4</sup> Lundqvist, E.K.& Klefstad, L. (In Press). Universitetssykehuset Nord-Norge - Regionsenteret for døvblinde, Tromsø ([www.unn.no](http://www.unn.no))

## **Usher Network**

### **Emma Boswell reports:**

With Lille seeming like a distant memory, the newly invigorated Usher Network has its work cut out re-organizing itself and preparing for a pre-conference seminar prior to the next ABDN conference scheduled for Belfast, Ireland in 2014.

The Network met amidst the excitement and inspiration that was the 8th European Dbl conference. Five member countries were represented during this very useful and productive meeting. We welcomed our newest recruit, Karen Wickham from Senses, Australia and even managed to include a member, Marion Felder, who joined us via Skype. This was thanks to the very helpful staff at the conference centre and some kind Sense colleagues.

So, we knew we had a hard task ahead of us; first working together as a new group, then planning for our Usher Network Seminar in Belfast. I am happy to say our group represents a healthy mix of professionals, including people with direct experience of Usher and those with a research background.

With that in mind the following roles within the Network our roles were decided: Emma Boswell (National Co-ordinator for the Sense Usher Specialist Service) was selected to Chair the network, and Nadja Högner (lecturer and research assistant at Humbolt University, Berlin Germany) agreed to serve as Deputy Chair. Other positions included Tatjana Bagdassaryan (Russia) who volunteered as Communication Officer. Marion Felder (Professor for rehabilitation and inclusion at the University of Applied Sciences in Koblenz, Germany), Constance Miles (PhD candidate in the Department of Disability and Psychoeducational Studies, University of Arizona, USA), and Karen Wickham (Social worker Deafblind Consultant with Senses Australia) agreed to be contact representatives for the Network.

We were lucky enough to have amongst our members two workshop presenters Constance and Karen; and Tatjana so dedicated that she travelled all the way from Russia, alone, just to attend our meeting! I also presented a workshop which helped identify priorities and gaps in services for Usher people, professionals that work with them and the families that care for them. My workshop was well attended and everyone contributed great ideas and issues from their home countries.

The Dbl Lille conference was a welcoming atmosphere, and with so many motivating plenary speakers and workshops happening around us, it spurred us on to plan to make our 2014 pre-conference seminar the best yet. We are currently designing the programme, thinking about suitable speakers and potential workshops. With next

year's Belfast venue booked and confirmed, our spirits are high and our to-do lists long!

For more information, please contact Emma Boswell ([emma.boswell@sense.org.uk](mailto:emma.boswell@sense.org.uk))

## **Denial, Shame and Pride<sup>1</sup>**

Emma Boswell is the national coordinator for SENSE as part of the Usher specialist team. While she has worked for Sense for seven years, she worked in the Usher coordinating role since 2011.

I'll talk about my background, experiences at different stages of life associated with shame and pride for Usher people and how this can be linked to mobility, communication and identity. Then I'll finally talk about the way forward, acceptance and adjustment for my conclusion, which will take us into the break.

A little bit about myself. I have Usher Type 1, together with eye cataracts and macular degeneration. I was a guide dog user but my guide dog has retired and I am on the waiting list for a new dog. I use mobility equipment such as canes. I work for the UK charity SENSE as the national Usher coordinator which means I head up the Usher specialist team.

My presentation is about shame and pride with respect to acquired deafblind people, of which people with Usher form one part of that group. I would say first that as regards shame and pride, those of us with acquired deafblindness have similarities with congenital deafblind people.

Like people in the general population people with Usher experience shame and pride at different stages of life, usually in a response to a life experience. For example, a teenager first diagnosed with Usher may be reluctant to use sign language. As they get older they relax a bit more and become more accepting of sign language.

Another person with Usher might be reluctant to use a communicator guide service. They may prefer to initially use a mobility aid, but through experience they may change this opinion and become accepting of this service. So, shame and pride is also the same for everybody as it is linked to achievements and failures. People with Usher will achieve the same as everybody else, they may go to university as I did or they may go into extreme sports.

I know people with Usher that have experienced bungee jumping or used a tandem bike; there are failures as well. For example I know people that have been learning to drive then fail their driving test and the same for the general population, they feel disheartened by this. But once they have passed their driving test it is a real sense of achievement of the different things people with Usher can accomplish. But some things may be short-lived because they may have to give up driving when their eyesight deteriorates.

The effects of changing vision does affect how people with Usher feel. This is recognized as a life crisis and does happens on average every five years after diagnosis. People with Usher have to be prepared to adapt and adjust to this diagnosis.

When someone goes on to university and experiences a different environment from their earlier school days, this can result in another life crisis. Other crisis may develop throughout other periods, including employment, raising a family, etc. During these difficult periods, we often see people come back to our SENSE service. People with Usher can experience a sense of embarrassment or shame linked to a number of issues, such as: mobility problems walking in a straight line; communication difficulties with lip reading or using their sign language and generally accessing information. In one example, I know a client with Usher, who travelling by train thought they were on the right platform yet actually got off at the wrong station because they couldn't hear the announcements that the train wasn't stopping at their proper station.

A very difficult issue with some people with Usher is they can lose their initial identity. For example, Usher Type 2 or 3 people born into the mainstream 'hearing identity' world become diagnosed as a person with deafblindness. They are thus torn between their old mainstream identity which they are used to now being part of the new deafblind community.

People with Usher often can be very self-conscious about how they fit into the world and society where people are looking at them and noticing whether they have mobility or communication issues. I know an 80 year old lady with Usher Type 1 who in her younger days had very good vision and was a prominent member of the deaf community. As her vision deteriorated with age, her field of vision gradually became narrower. She began to miss what people were talking about in large groups and eventually couldn't see people even in her line of vision. As communication became more difficult for her she actually withdrew from the deaf community leading to a real sense of shame.

Referring back to mobility problems, people do feel embarrassed and shameful about using mobility devises like a cane. People with Usher have problems in dark, badly lighted situations, like restaurants. In environments without any colour contrast, like a glassed conservatory, a person with Usher might not know where the door is located, leading to further feelings of shame and embarrassment. While they may feel the first step into a room, if there's no colour contrast this can lead them to fall over.

While I've spoken about how people with Usher can feel a sense of shame there are many positives that can lead to a sense of pride. Example include getting a new guide dog or learning how to use a communicator guide service. We very much encourage people to become positive role models at SENSE. They may feel proud they've learned new communication methods, like hands-on sign language or learning Braille. For communication they may become advocates for those methods which may lead to a sense of pride about this new accomplishment. What can be a life crisis for one individual can be a sense of pride for another.



Different clients react differently to their change of circumstances. For example, an Usher Type 3 client may become very adept with using a cane, while another client I know (which is the same for me) may be reluctant to use this mobility device. Myself, I have in my backpack a cane but rarely use it unless in an unfamiliar situation. Other people may be very proud they have a lovely cute guide dog that people want to come and stroke and have an attachment with; that's very much how I felt. But other people I know really don't want the responsibility of having an animal or pet in the home.

So every client we come across has a different perspective to these issues. An Usher Type 1 client that I know with poor balance is reluctant walking in strange environments as they might get dizzy. Many Usher clients I know are more brave to walk around, will complain that they trip over people walking, people biking, children running, etc.

One client I know that was very fond of cycling when their sight was good, later began to cycle in the middle of the road when forced to use a tandem. They are very proud of how they've overcome this barrier.

For sign language users, mainly those with User Type 1 and some Type 2, they are very proud of the fact they use sign language. Usher Type 2 and Type 3 individuals generally don't know sign language, which creates a sense of shame that they can't communicate with Usher Type 1 people. Those with Usher Type 2 might miss what people are saying in noisy situations with background noise.

There are numerous communication breakdowns that we as Usher people will experience, especially when meeting new people. For example when you meet somebody in a darkened room you might be able to grasp what they're saying by lip-reading; then that person will leave and say goodbye to you. A few weeks later they may come up and say "Hi Emma, so nice to meet you", because I met them in a darkened environment. I don't recognise them and people may think I'm rude.

Having said this, some people might be very proud of the communication skills that they have. We're seeing more and more clients with cochlear implants meaning they can continue using speech for which they are very proud.

Having communication skills are a sense of pride for Usher people that we know. When they're first diagnosed with Usher, some will feel a sense of shame and won't want to tell anyone. If working they'll want to keep it a secret from their employers or boss.

Clients eventually learn to develop acceptance of the condition, then become proud of the fact they have Usher. They're very proud they know their communication access needs and they'll tell everybody what they know. So at SENSE we see a very broad spectrum of clients and observe how they react to things that are happening to them and life experiences they are having.

And now I'll move on to acceptance and adjustment. My suggestion is that we should encourage people we meet with Usher that they learn as much as possible about their own eye condition. The more information they have about their Usher Syndrome, the more they can control and adapt to their situation. Clients with Usher should be reminded that there may be times they will be ignored, be misunderstood;

this happens to everyone as it is part of life and not just or because of their Usher Syndrome.

In conclusion, I have talked about the sense of shame and pride that people with Acquired Deafblind Usher, in particular, feel. As a professional, meeting many clients with Usher I tell them it is important to remember they're all individuals and react to things very differently. The emotions they feel will be very varied. Usher people can and do overcome their sense of shame and will become proud of the things they're achieving.

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<sup>1</sup> Presented as a response to a plenary titled 'Denial, Shame and Pride', presented at the 8th Dbl European Conference, Lille France, August 25, 2013

## **International Youth Network**

### **Simon Allison reports:**

The Dbl European Conference in Lille, August 2013, provided the opportunity to share with delegates the proposals for a new youth network.

During the focus group sessions, there were discussions centered on the main purpose, aims and objectives of the proposed network. It was agreed that providing a collective international platform for young deafblind people will highlight their positive contribution to society.

The sessions attracted an input from both deafblind young people and specialist professionals from many countries. We shared examples of how deafblind youth projects had made an impact on local communities. Jake Murray, a young deafblind person from Scotland, explained how the 'One Giant Leap' project had provided a forum for young deafblind people to share views, develop ideas and create peer group friendships. Shirley Rodrigues Maia gave an account of a deafblind youth project in Brazil and expressed interest in the youth network. To conclude the sessions an audio descriptive slide show was presented showing just how active deafblind young people are throughout the world.

On the final morning of the conference, attendees from the focus group met to devise an action plan to develop this proposed network.

A summary of the action plan to be implemented following Dbl approval:

- Form a network constitution committee. Posts will include chairperson, secretary, treasurer and information officer. Where possible these posts should be offered to deafblind young people.

- Recruit 'country coordinators'. These would be people that have a good understanding of the provision for deafblind people in their own country and would be prepared to promote and support the activities of deafblind youth.
- Participate in future Dbl conference events, including preconferences.
- Organize activities such as summer camps and exchange visits. (Delegates from Kentalis and Deafblind Ontario suggested venues for a summer camp in their own countries.)
- Create opportunities for deafblind young people to access Dbl social media such as facebook and twitter. Invite Deafblind young people to contribute to Dbl publications such as the Dbl review.
- Create a publication containing a collection of testimonies produced by young deafblind people.
- Seek out sponsorships to raise funds for network activities.
- Work in collaboration with other Dbl networks.
- Organize a data base of contact information for individuals to receive updates about the network.

In summary, the Dbl Lille conference provided an opportunity for a very positive starting point for the proposed network with its enthusiastic membership.

Organisations that are supporting the network proposals include:

Royal Dutch Kentalis (Netherlands); CRESAM (France); Deafblind Ontario Services (Canada); Able Australia; The Anne Sullivan Centre (Ireland); Grupo Brasil; FAM Quenehem (France); Helen Keller National Center for Deafblind (USA); Perkins School for the Blind (USA); Sense Scotland; Sense (UK); Norwegian Support System for Deafblind; National Institute for the Blind and Deafblind (Iceland); Sense International (Romania)

For further information on the proposed youth network and how you could support it, contact: Alan Avis ([alan.avis@sense.org.uk](mailto:alan.avis@sense.org.uk)) or Simon Allison ([simon.allison@sense.org.uk](mailto:simon.allison@sense.org.uk))

## **Preparing an Individual Relocation Profile and Plan<sup>1</sup>**

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How can we best support our clients when they are moving to another accommodation? This question arose when our clients within Bartiméus organisation needed to move into their new group homes. Since 2006, a large reorganisation of the housing within Bartiméus has been occurring in different phases. At the end, just

over 400 of our clients will have moved (some twice) into some 43 new houses. Eight of these new homes were specifically designed and built for people with deafblindness.

## **Supported living for persons with deafblindness at Bartiméus**

Since 1980, Bartiméus has provided special care for persons with deafblindness in the city of Doorn in The Netherlands. Recently, a total of eight new houses were built, providing optimal living conditions for persons with deafblindness.

These homes were designed and fitted with resources to facilitate orientation and communication for the individual residents. Special features can be found in each home, for example, tactile orientation boards on the walls which are painted in contrasting colours. Special attention is paid to the individual's communication needs and preferences. The houses for persons with deafblindness are designed to feel like home, providing suitable space for recreation and personal development. The entire process of moving did not only entail the relocation of clients into new houses, but for some it also meant getting to know new care workers, new fellow residents, new routes to places at our facility, etc. Moving house is indeed a big change?

### **Moving: a life-changing event**

Moving to a new house is considered a life-changing event<sup>1, 2</sup>. There is clear evidence that stressful life changing events can be a risk factor leading to such psychological problems as affective or mood disorders, adjustment disorders, and personality disorders<sup>3</sup>.

Although such life events are marking a big change in one's life, it doesn't mean it has to be a negative one. If the change serves to improve an individual's quality of life, there may be fewer or even no negative effects<sup>4</sup>. Whether a life event is experienced as positive or negative is ultimately determined by how a person experiences the change<sup>4</sup>. Thus, it is very important how a change is experienced. Taking this somewhat further, how one experiences the life change event can also be influenced by the people surrounding that person.

To guide the individual through the change and help him/her cope with the situation, we need to know more about the individual's characteristics and his/hers current and future situation. For this, the Bartiméus Expertise Centre Deafblindness developed the 'Individual relocation profile and plan', which was presented at the 8th Dbl European conference in Lille, August 2013.

### **The individual relocation profile**

For each individual being relocated, a relocation profile was developed based on the following information known about each individual: sensory and communication abilities, cognitive functioning, medical and psychological information, etc. This information is summarized to prepare staff to understand how the individuals might

participate themselves in their move, how they might be affected by the move, positively or negatively, etc. Completing this profile will allow personnel to complete the next section - the individual relocation plan.

### **The individual relocation plan**

The individual relocation plan is divided into three stages:

- Preparing the individual for the move before moving day;
- Supporting the individual during the actual moving house day
- Supporting the individual to cope with the changes to their life that have occurred following moving day.

As part of these individual plans, the following aspects need to be considered for each phase:

- Communication - Does the individual know what moving is?
- Social-emotional - Does the individual have to say goodbye to certain persons?
- Mobility - Will the individual need to learn new routes within the house and outside? What can you do in advance?
- Interior design - Will new furniture need to be ordered or is it important that the same furniture comes along?
- Daily schedule - Will the daily schedule of the individual change?
- Input from family members and friends

In this way a well thought out relocation plan is developed for each individual to ensure that their relocation proceeds according to the best knowledge available about how each individual will manage and cope with this major event in their lives. Moving house can be a big change, but it can definitely be enjoyed when the process is well prepared!

### **Bartiméus Publication**

The brief summary outlined above is further detailed in the Bartiméus publication: 'Individual relocation profile and plan - Supporting children and adults with intellectual and sensory disabilities when moving house'. This publication was produced to provide detailed information applicable when someone moves within a residential facility, moves from their family home to a facility or from one residential facility to another. The book provides guidelines and tips to ensure that the moving process runs as smoothly and efficiently as possible and with a minimum of stress to the individual. This publication is available in both English and Dutch and can be ordered at [http://www.nl/publicaties\\_shop\\_product/84149](http://www.nl/publicaties_shop_product/84149).

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<sup>1</sup> Workshop presentation titled 'Supporting People with Deafblindness Moving House', 8th Dbl European Conference, Lille France, August 27, 2013

## **Parenting and Usher Syndrome<sup>1</sup>**

### **Shared Experiences of Parents with Dual Sensory Loss**

Being a parent is a demanding challenging job in the best of circumstances. But how do you manage if you have a dual sensory loss? Like all parents, people living with deafblindness find having children a life-changing experience, which can be stressful, worrying and frustrating, along with full of joy and discovery.

I was interested in delving further into the parenting experiences of people who are Deafblind. Through this research and questionnaire I hoped to identify some themes and issues that are commonly faced by parents with dual sensory loss, with a view to: helping raise awareness about the challenges and the successes experienced by parents with Ushers Syndrome; aiding our organisation to provide better support long term to parents and families, and to advocate for more relevant support services for the Australian Deafblind Community.

A literature review on this topic found very limited research available specifically related to parenting with Ushers Syndrome or a dual sensory loss. There was slightly more information about parents who are Deaf or Blind but these did not address the unique issues faced by parents with a dual sensory loss.

Much of the research available appeared to be driven by a search for problems, conducted from a medical model perspective and tended to pathologize parents. A significant amount of the literature was focused on parenting capacity and the perceived impact of this on children, with less attention paid to social environment, family context or economic factors.

### **Some common emergent themes**

Some common themes that did emerge from the literature, for both groups, deafblind specific and heterogeneous groups of parents with disabilities included:

- The importance of appropriate effective communication support and access to services and information.
- An overall lack of informed professionals to provide services and information to the Deafblind community.
- Limited access to information about contraception, family planning, birth, child rearing and parenting in accessible formats for people who are Deafblind.
- Parents were all too often absent from research agendas particularly with a focus on social environment, family context or economic factors.
- Repeated validation of the importance of contact with other parents with dual sensory loss and support networks.
- Spousal/Family support was documented as invaluable support.
- For Deafblind parents specifically, there was some research surrounding the loss of roles and the impact of this on individuals and families. People with Usher can experience a loss of the roles that define them (parent, worker, homemaker, confidante, caretaker). The resultant depression, suicidal ideation, mental health issues etc was fairly well documented in the limited data available.

### **Questionnaire**

The design of the questionnaire utilized for this research gave prominence to the parent's views and experiences with an aim to identify and reduce barriers to parenting and promote better support to parents.

Participants had children from babies through to adult children; were diverse in class/socioeconomic position, employment, ethnicity, partnership status, age and previous experiences of parenting. (For a copy of the questionnaire and a more detailed report, please contact the author directly)

The questionnaire was divided into twelve blocks of questions, with results summarized as follows:

### **Participants profile:**

Twelve individuals, seven males and five females ranging in age 32-75 years, participated in the study. Ten from Australia, one from Canada and one from Switzerland. Ten had Usher syndrome and two with Dual Sensory Loss (DSL) from other causes. Of the 12, five had oral language, six were Auslan users and one was a tactile finger speller. Seven of the individuals had hearing partners while five had deaf partners. Nine couples were still living together in the family home, one family had a co-parenting arrangement, one parent was living with a new partner and one was a single parent. Only one family reported having children (2) with a hearing impairment. No children were reported as having a diagnosis of Usher Syndrome.

## **Becoming Parents**

This block of questions included queries about preplanning, genetic testing, support and information received. The majority of participants did not engage in any genetic counselling, some did not have the diagnosis of Usher prior to starting a family and those that did seek advice, made an informed decision and decided the risk factor was well worth it.

## **Prenatal, delivery and post natal care**

In this block the focus was on prenatal, post natal, delivery care and support experiences. I found that there was a generational influence related to the expectation of having communication support (obviously far greater in the younger generation as interpreters are much more accessible than they were 20-30 years ago). Only one participant reported suffering from post natal depression which is lower than the National average

All participants reflected on the importance and value of family support during this stage of their parenting journey.

## **Caring for a young baby**

This group of questions covered bringing home and caring for a young baby. Highlighted was particularly the fatigue related to deafblindness and how difficult this is coupled with the usual fatigue of caring for a baby. There were several comments around being and feeling safe in the outside/community environment with a young child. Some participants reported distress at the lack of confidence shown primarily by partners at their ability to cope with caring for a young child. Practical issues around transport and the ensuing isolation were significant. All parents were proactive in coming up with strategies to ensure the safety of their child.

## **Bonding and communication**

This section questioned how parents bonded with their children and any implications on their communication with their children due to their DSL. All participants reported that they bonded closely with their children and it appeared that all children formed a secure attachment.

The importance to the parents who are Auslan users that their children had experiences of both hearing and Deaf language and cultures was stated along with participant's experiences of communication actually being enhanced due to their DSL. All parents were proactive in trying to educate their children regarding the best ways and the best environment for communicating fully with their parents.

## **Educational experiences**

This block of questions covered the educational setting and parents experience communicating with schools, teachers and staff. All parents reported at some stage feeling isolated and excluded from their school community due to their hearing loss.



They were proactive in trying to find solutions to ensure they were included in their children's educational progress but overall increasingly tended to withdraw from this community due to communication difficulties. Participants reported that the majority of their school age children took on additional responsibilities regarding informing their parents and trying to include them in the process, the children often reported disappointment that their parents could not be more involved.

### **Explaining dual sensory loss to your children**

In this section parents shared how they explained their dual sensory loss to their children and how their children coped with this information at different development stages. Parents expressed concerns at burdening their children and most felt that their children had not fully grasped the implications of their DSL and the disease progression.

### **Young Carers**

This block of questions explored how the participant's children engaged with the Young Carers role – interpreting, sighted guide and other support roles at different developmental stages. Participants reported that at a younger age children were generally happy to participate and support but once adolescence hit for some participants the common teenage problems with parents (communication, embarrassment, peer pressure, etc) influenced their child's experience and willingness to support. Several parents did highlight the positives that the caring role had had on their children's development.

### **Relationships**

This set of questions related to the impact DSL has had on their relationships with friends, other parents, members of the community etc. Participants reported an increasing isolation as their vision deteriorated impacting significantly on the opportunities to form new relationships, accessing employment and making social connections.

Almost all participants recognized the need to raise awareness of deafblindness within the Deaf and hearing population as a means to support people who are deafblind to lead a normal life. Auslan users reported that they are at times further ostracized from the Deaf community due to their vision loss.

### **Grief, guilt and loss**

All participants reported experiencing feelings of grief and loss in regard to their loss of roles and inability to perform tasks related to parenting as their vision deteriorated. The majority of parents expressed feelings of guilt when they could not help their children participate in 'normal' childhood activities ie: sleep overs, tuckshop, mums taxi, watching their kids play sport etc. The loss of independence,

uncertainty and constant readjustment to their deteriorating vision was stated as a significant challenge.

Concerns were also stated regarding the ability to retain employment and provide for their families. Spousal and family support, appropriate professional and social support that helped to foster a positive attitude and provided workable, functional and emotional coping strategies appeared significant in assisting parents to deal with these issues.

### **What has been helpful?**

All participants reflected on the value of family support, networks and peer support groups. Some participants reported that it is only in their middle age that they have met other parents with Ushers and encouraged others to seek out this form of support sooner rather than later. There was also an acknowledgment of the importance of acceptance, personal growth and suitable counselling and support to help parents living with deafblindness adapt and work through their issues.

### **The future**

In response to questions concerning worries for the future for their children as one aged and vision deteriorated, participants reported a variety of concerns: staying connected with their families and community, retaining employment, etc. The uncertainty surrounding disease progression was significant for some participants along with the loss of independence and the potential that they will become a burden to their children.

Some participants were hopeful for the future regarding stem cell and gene therapy. Several were very confident that there would be a cure or at least a treatment in their lifetime. This hope helps parents to deal with the day to day stresses of parenting and living with their dual sensory loss.

### **Where to go from here?**

- Further research is necessary, nationally and internationally, to develop methodologies to assist people who are deafblind on their parenting journey.
- Collect statistical data on the number of deafblind parents in Australia so as to have a potentially larger sample size for any further studies.
- Develop a national information resource service for Deafblind Parents, similar to Through the Looking Glass (an organization in Berkeley California that serves as a clearing house for information and advocacy for parents with disabilities)  
<http://lookingglass.org/home>
- Increase the availability of support networks to provide better access to information for people who are deafblind who are parents or who are planning to become parents.
- Develop tools to raise awareness on the issues faced by parents that are deafblind.

Parenting is one of the most private, intimate roles that we can undertake; and at the same time is a responsibility subject to the greatest public gaze and scrutiny. Ultimately, parenting is about loving, guiding, caring and nurturing, disability status aside. I would like to take this opportunity to thank the people who participated in this research so generously and honestly and I hope that in some way their efforts will be ultimately be rewarded with an increased awareness, further research and ultimately more resources and supports for parents who are living with a Dual Sensory Loss.

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<sup>1</sup> Workshop presentation, 8th Dbl European Conference, Lille France, August 27, 2013

## **Let's keep in touch**

**Monique Snelting, MSc. Speech Therapist, Royal Dutch Kentalis, the Netherlands.  
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Human development is a cultural process. As a biological species, humans are defined in terms of our cultural participation. We are prepared by both our cultural and biological heritage to use language and other cultural tools and learn from each other.

Through contact between persons, there is always such non-verbal communication as gaze, gestures, facial expressions and postural changes. One of the most powerful forms of nonverbal communication occurs when people touch. As we all know, culture has a major influence on touch in a social contact. Touch means different things in different environments and touching behaviour can be affected by our cultural background.

For a person who is born deafblind, touch is a very important sense. The hands and the body take over the functions of the visual and auditory senses. Thinking about the cultural differences in the way different communities use touch, the question arises: what does it mean for a person with CDB to be born in a particular culture?

Based on theories of several anthropologists, we may expect that caregivers from different cultures use the tactile modality in a different way in interactions with their children. But can we really see these differences when it comes to the interaction moments between caregivers and their CDB child? Or is it possible that we cannot see differences because caregivers of a child with CDB naturally adjust to the tactile needs of their child by spontaneously using more touch during these interactions? The answer to these questions is simply, yes, caregivers can adjust to the special, tactile needs of their child with congenital deafblindness; but it takes place against the backdrop of specific cultural elements.

### **Contact or non-contact cultures**

In the literature, the technical term 'culture' is used in discussions about development and should not be confused with the popular notion of being 'cultured', which usually refers to people who, for instance, have acquired refined manners. Culture consists of human designs for living that are based on the accumulated knowledge of people that has been encoded in their language and embodied in the physical artifacts<sup>1</sup>, beliefs, values, and customs that have been passed down from one generation to the next (Cole & Cole, 1996)<sup>2</sup>.

Culture is categorized by anthropologists into two types: contact and noncontact cultures. Contact cultures refers to people who are interacting who face one another more directly, interact closer to one another, touch another more, look another in the eye more, and speak in a louder voice. People from Africa and Southern Europe are considered having a contact culture. Asians, Americans and Northern Europeans are recognized as people with a noncontact culture (Hall & Knapp, 1992)<sup>3</sup>.

In contact cultures, infants are in constant contact with their caregivers and tactile forms of communication are readily available. Being in constant close contact with a caregiver makes it easier for an infant to employ such nonverbal cues as gestures, facial expressions and gazes. From the perspective of hearing and seeing persons, the cultural environment is more accessible to gain information from in order to acquire specific cultural behaviour. For a person with CDB, the meaning of culture and cultural behaviour must come from bodily experiences. In other words, for a person with congenital deafblindness the whole body plays a role in getting information from the world; essentially the body becomes a tool for expressing themselves. All human beings can communicate something by touch, but a person with CDB is likely to be able to read bodily impressions more sensitively than hearing and seeing people. Realizing this, we should expect that a child with congenital deafblindness is better off in a contact-culture, simply because tactile forms of interaction and communication are more accessible. But do we see this reflected in practice?

### **Let's go into practice**

For the Masters Programme in Educational Sciences Communication and Congenital Deafblindness at the State University Groningen (Netherlands)<sup>4</sup> a case

study<sup>5</sup> was done by the author on the impact of culture on the tactile modality during spontaneous interaction moments between a caregiver and their child with congenital deafblindness.

This study was carried out with video analysis of two - caregiver- CDB child couples. One couple from the Netherlands represented the non-contact culture, while a couple from Ghana represented the contact culture. The focus in this study was on the tactile interaction between caregiver and a child with CDB.

Video clips used in this study were from the private collections of the participating families. Only a small sample of footage was chosen for the analysis. In clip 1, Molly from Ghana sits on the back of her caregiver while she is dancing in the room in the presence of other family members. The radio is playing loud music and the caregiver is dancing to the African rhythm. Most of the time in this clip, Molly sits on the back of the caregiver; but in the last part she gets down and is able to move in the room by herself. In clip 2, Lotte from the Netherlands is playing with the caregiver on a big, pink pillow which lies on the floor in her specially designed room. The aim of this study was to observe any differences in the quality of the tactile modality between caregivers and their child with CDB from the perspective of two different cultures. To describe the analysis in more detail, the concepts of bodily actions, amount of touch, locations of touch on the body, turn-taking and mutual attention were used.

Describing and analysing every second of the non-verbal bodily interaction, both from the perspective of the caregiver and the child with CDB, gave surprising results! When analysing both clips, it was observed in both of the clips that there was tactile contact which could be intentionally directed towards the other. We define tactile contact as moments whereby there is bodily contact, in every manner and on all possible locations on the body. It may be that both partners in the interaction touch each other, but also that one of the partners is touching the other. An unexpected observation was made - in both clips the amount of the use of touch during the interaction was almost equal!

But there were also big differences. The positioning of the participants in the interactions looks different from each other. For Molly and the caregiver, interaction occurs when Molly is behind the caregiver. For the Lotte-caregiver interaction, Lotte sits in front of the caregiver. Because there is a different perspective in both clips, the experiences of the movements and bodily actions from all the participants in the interactions vary.

The different perspectives adopted in the interaction moments means that touch is experienced in different locations on the body. When you're sitting on someone's back, it is obvious that the bodily actions are focussed on the back of the body. In face-to-face interaction the focus of touch is on the front side of the body.

Another difference has been seen in interaction patterns. Based on the visible turn-taking moments during both interactions, it is clear that the turn-taking moment of the non-contact culture couple shows a higher number of turns than the turn-taking moments of the contact-culture couple. It is more difficult to distinguish turn-taking patterns in clip 1 because Molly is sitting on her caregivers back and follows all the movements made by the caregiver. It is possible that there are some turns in this interaction which are not easy to see. For example, a light pressure of Molly's legs

against her caregiver's hips (an initiative to seek repetition) cannot be observed by the researcher. And conversely, the possible response of the caregiver is not clear enough to be differentiated as a turn, even when the initiative wasn't clear in the first place.

Mutual attention can be seen in interactions between persons with CDB and their caregivers and is evident from the posture and actions of the persons who are interacting - for instance eye-contact or bodily actions that address the other. There was a striking observation in clip 2 because of the position of the child (on the back). It is difficult to determine whether the focus is towards each other or not. Shared attention on each other cannot be explained through eye contact or movements directed towards each other. It is not clear if there is focus towards each other, simply because it is not always visible. For almost half of the duration of clip 1, it was not clear if there is mutual attention or not.

## **Conclusion**

In this case study we have observed that it makes no differences for the child with CDB, despite their cultural background, that the interaction with the caregiver takes place. Both children have nearly as much access to tactile interaction, but the interaction takes place against the background of specific cultural elements.

To gain new experiences, the biological or environmental factors could have an effect on the interaction - congenital deafblindness being a biological factor. Further, environmental factors are subject to the influences of a specific culture. In this study while there were differences in the use of the tactile modality between the caregivers of the children with CDB from the two different cultures, there were also surprising similarities.

There are variations in how touch and tactility are used and these variations could be explained in several ways. However, in these cases, CDB is the strongest factor influencing the tactile relation compared to what may be expected from the typical cultural differences. This means that CDB provides the similarity in the use of the tactile contact between these two cultures, but they take place in different cultural contexts.

In the analyses of both interactions observed in both clips, we can see concepts which could increase the quality of the interaction itself, such as shared attention, mutual attention, turn-taking etc. These are all indicators of a good quality use of touch in the interaction. However, based on this view we cannot suggest which of the two interaction moments have a greater quality use of touch for the child with CDB.

Besides the differences in experiencing touch based on cultural background, in this study both children are CDB. So there appears to be a biological factor which influences the tactile interaction. We can only rely on the non-verbal signals of both children, to estimate what could be described as a positive quality and what could be described as a negative quality.

There are similarities found in the results of this case study. There is in both clips mutual engagement and emotional involvement in both interactions. While touch is

considered universal, we could suggest that also having fun together and mutual attention is a universal phenomenon in the context of these interaction moments between these caregivers and the two CBD children.

Despite the different cultural perspectives in the two cases, both caregivers try to create a space whereby respect and trust can be seen. This does not seem to be related to a specific culture, but derived from the affection of the caregiver in relation to the child with CDB. It could also be that the caregiver adapts to the tactile needs of their child with CDB, each in their own way, influenced by their cultural traditions and habits. It seems then that as a matter of course, both caregivers use touch in contact with their child with CDB, regardless of what they are accustomed to in their culture.

We can specify that there could be differences in the way caregivers from several cultures make use of the tactile modality in interaction with their child with CDB. But recognizing the fact that interaction could be influenced by environmental, biological and individual factors, we cannot make a clear statement on the impact of the cultural influences on the use of the tactile modality in interaction. It is important that we acknowledge the differences in the use of touch in various positions and that we can learn from each other and are open for new forms of tactile contact.

There is not a perfect form or background from a specific culture to use the tactile modality in contact with a person with CDB. However we can learn from various cultures and incorporate the favourable influences that strengthen the contact, interaction and communication with persons with CDB. The context could be different and probably cultural specific and this could cause typical interaction patterns, but the factor 'deafblindness' in the interaction in this case study ensures that both caregivers seem to use the tactile modality consciously which is so important for their children in order to learn and gain new experiences in their own way.

<sup>1</sup> Physical artifacts can have a tangible part (material) and temporal (exists in time)-  
<http://www.cyc.com/kb/physical-artifacts>

<sup>2</sup> Cole M. & Cole S.R. (1989). The Development of Children

<sup>3</sup> Knapp, M.L. & Hall J.A. (1992). Nonverbal Communication in Human Interaction, (3rd ed.)

<sup>4</sup> <http://www.rug.nl/masters/educational-sciences-communication-and-deafblindness/>

<sup>5</sup> Snelting, M.E. (2012). Let's keep in Touch! The impact of culture on the tactile modality in interaction with a child with congenital deafblindness. MSc Thesis, University of Groningen, The Netherlands

## **Introducing...**

### **A CHARGE pack for practitioners**

- An information pack for practitioners working with children and young people with CHARGE syndrome.
- Each topic area has been written by an established authority on the subject.
- It also offers basic information for professionals who may rarely come into contact with children with CHARGE.

### **How did it come about?**

- It was requested by families who continually have to explain about CHARGE each time they meet a new professional.
- The topics have been chosen following consultation with a range of practitioners who work with children with CHARGE, and as a result of a questionnaire returned by approximately 70 families. We have also consulted with the practitioners the pack is aimed at.

### **Where can I get it?**

- It will be available to download free from the Sense website from 28th November at [www.sense.org.uk/chargepack](http://www.sense.org.uk/chargepack)
- A limited number of printed copies will be produced, with factsheets in a folder.

### **What topics does it cover?**

- An overview of CHARGE; Diagnostic criteria; Genetics and Endocrinology; Anaesthesia issues in CHARGE syndrome
- Audiological assessment; Cochlear implants
- Clinical assessment of vision
- Visual behaviours, implications and possible support strategies
- Sensory integration and Communication
- Eating and drinking; Sleep
- Early development; Early intervention and support
- Education, Behaviour and Mental health issues; Social and emotional development
- The roles of the intervenor, health visitor, general practitioner, occupational, speech and language therapists, social worker
- A parent's perspective; Adulthood and Multi Agency working

For further information, contact [knowledge@sense.org.uk](mailto:knowledge@sense.org.uk)



## **Sense International receives grant**

### **to improve access to education and support services for deafblind people in Peru**

The Big Lottery Fund<sup>1</sup>, the largest distributor of National Lottery good cause funding in the UK, recently awarded Sense International<sup>2</sup> £499,687 to support deafblind people in Peru.

The project will improve the primary education, livelihoods, health and human rights of deafblind children and adults and their families in South America. The funding will provide training for teachers to help them communicate with and better support deafblind children in the classroom. Sense International Peru will also share their experiences of advocacy and provide training to other professionals and partner organisations in Bolivia, Ecuador and Venezuela that will benefit deafblind children and adults.

Sense International has been present in South America since 1995. In 2003 it supported the opening of the Helen Keller day centre for deafblind people and in 2004 Sense International Peru was established to support development of an infrastructure of services and advocate for deafblind people. Its mission is to help deafblind children and adults to live, learn and thrive.

James Thornberry, Director of Sense International, said: "Sense International supports deafblind people in Bangladesh, India, Kenya, Tanzania, Peru, Romania and Uganda and without support many will lead short and lonely lives. This funding will allow us extend our work in Peru and across South America and help ensure that more deafblind people than ever have access to an education and the support they need to go on to lead full and productive lives."

Peter Ainsworth, Big Lottery Fund UK Chair, said: "This funding will bring real change to the lives of deaf-blind children living in areas where access to the right education, care and support is vitally needed but not readily available. The Fund is supporting grass roots work tackling the causes of poverty and deprivation, to help improve the lives of some of the poorest people across the world."

<sup>1</sup> [www.biglotteryfund.org.uk](http://www.biglotteryfund.org.uk)

<sup>2</sup> [www.senseinternational.org.uk](http://www.senseinternational.org.uk)

## **Death of a Prominent Person in the field**

**Dear Dbl members,**

I am sad to report that Joe Morrissey died suddenly at his home in Tanzania, in mid January 2014. Joe was known to many of us and was widely respected for his longstanding contribution to deafblindness. Although a huge influence, he is probably best known for his outstanding work in East Africa. Joe established schools

and set up units, still flourishing today, that have changed the lives of many children and families.

We all know that Joe did his amazing work with great humility. He was a gentle man who gained the immediate respect of everyone he met. Joe is a great loss and will be sadly missed. Our thoughts are with his family and friends at this most difficult of times.

On behalf of Dbl

**Gillian Morbey, President**

## **15th European Rehabilitation and Cultural Week of the Deafblind (Ercw) 2014**

**Visegrád, Hungary, 25th – 31st August 2014**

### **First Announcement**

The European Deafblind Union<sup>1</sup> is pleased to invite individuals to participate in the 15th European Rehabilitation and Cultural Week of the Deafblind (ERCW) 2014. ERCW 2014 will take place in Visegrád, Hungary from 25th to 31st of August, 2014 hosted by the Hungarian Deafblind Association (Siketvakok Országos Egyesülete) which is celebrating its 20th anniversary.

Visegrád is a small town with about 1600 inhabitants situated 43 kilometers north of Budapest on the right bank of the Danube River in the picturesque area of Danube Bend. You can read more about the town at [www.visegrad.hu/en/](http://www.visegrad.hu/en/).

Hotel Visegrád, the venue of ERCW 2014, is located in the center of Visegrád. The hotel has single rooms, double rooms, triple rooms and family rooms. Hotel details are available by email: [info@hotelvisegrad.hu](mailto:info@hotelvisegrad.hu) and website [www.hotelvisegrad.hu/en/](http://www.hotelvisegrad.hu/en/)

'Back to the renaissance' is the motto of the ERCW 2014 in Hungary. In the atmosphere of the historical places you can touch the past with the following options: Royal Palace and Citadel in Visegrád, Knights' Tournament and Royal Feast, Court of Crafts in the Palace House, visiting in the towns of Esztergom and Szentendre.

The preliminary program, including Social and Leisure activities (examples Picnic lunch on the Telgárthy Meadow and Boat trip in the Danube Bend, etc) will be available in the Second Announcement coming in February 2014.

This event will provide an opportunity for The European Deafblind Union (EDBU) to celebrate, almost one year later, the 10th Anniversary of its founding in Denmark in October 2003. It is also the opportunity to celebrate the 15th anniversary of the EDBU Interim Board established in Finland in September 1999.

On the occasion of this double anniversary, a worthy ceremony will be organized with the participants at the ERCW 2014. The organizers would appreciate if some of the participants will make short performances in any genre individually or in group. If intending to make a performance, please request a Performance Registration form in addition to the other forms.

The event has established the following individual fees for all participants (shown in Hungarian currency, HUF) which includes accommodation, full board, bus transfers and programs: single room (145 000 HUF); double room (120 000 HUF) and triple room (110 000 HUF) person. Note that family rooms are available for 4 persons, with fees similar to the triple room rate. Fees to be paid by bank transfer only.

If interested in the ERCW 2014 Visegrád, Hungary, please contact Tamás Gangl, President Hungarian Deafblind Association by email ([ercw2014@gmail.com](mailto:ercw2014@gmail.com)) to obtain the appropriate Registration and Accommodation forms and information on payment of fees.

The deadline for registration and payment in full is 31 March 2014.

## **Prestigious awards presented**

**at the 8th Dbl European Conference, Lille France, August 28, 2013**

During the Gala Dinner at the 8th Deafblind European Conference in Lille, France, recipients of the Dbl Lifetime Achievement and Distinguished Service Awards were honoured.

The Lifetime Achievement Award is presented to an individual who has made a distinguished contribution to services for deafblind people on a national and international level. Previously only 5 persons have been honoured with this award. The Distinguished Service Award is offered to people who have significantly contributed to the deafblind field, or Dbl internationally.

### **Lifetime Achievement Award**

Deafblind International is pleased to present the Lifetime Achievement Award to David Brown who has dedicated his life to the needs of individuals who are deafblind.

In his early career with SENSE UK, David helped to develop and manage early childhood and family services. He later was sought after by professionals for his work on the “forgotten senses” particularly proprioceptive and vestibular. He has helped many understand that deficits in these senses contribute to behavioral challenges for children.

In one letter of support the writer indicated that “he is one of the most brilliant people I know “. He described him as a person “who has an uncanny ability to understand the experience of someone who is deaf-blind and to create change for that person”.

David has had an international impact on the field of deafblindness. His work spans the globe and he has spent hours helping professionals, deafblind individuals and families in Germany, the UK, Australia, New Zealand, Canada and the United States. In addition to his regular job with California Deafblind Services in San Francisco (USA) he travels and shares his knowledge with his colleagues.

His focused work on CHARGE has changed the lives of so many children. He alerted professionals to the fact that individuals with CHARGE were experiencing tremendous stress. He guided professionals and parents to understand the child's situation and to reduce the stress in order to provide a good quality of life and educational opportunities.

In addition to his daily work and providing training to colleagues in the field, he has found time to write articles to share his knowledge with others in numerous publications, including Dbl Review, American Journal of Medical Genetics, and as Chapters in Books published in the USA and Germany.

### **Distinguished Service Awards**

Deafblind International is so proud to present the Distinguished Service Award to Dominique Spriet.

Dominique Spriet has dedicated her life to providing quality programs for individuals who are deafblind. Her career started as a trainee at Conover Hall in the UK working for several months in the deafblind unit. This experience inspired her to study Special Education. After graduating she worked in Australia at the Royal Institute for Deaf and Blind Children in the deafblind unit. After her journey around the world she returned to France and was appointed as the head of the Education Department of a new school in Chevreuse near Paris for children who were deafblind. After this experience she was appointed in 2001 as the Director of a Center for Children with multiple disabilities.

Her love of individuals who are deafblind always was her focus. Her dream was to create a fully accessible center for adults who are deafblind to ensure the individuals could participate fully in their lives. This dream became a reality and she had to work with the architects, contractors and community to create the center that now provides a high quality of living for 43 individuals who are deafblind. The center opened in 2007.

Deafblind International has benefited from Dominique's skills for many years. She served on the Board of Dbl and in a calm and thoughtful way would share her thoughts on the strategic direction of Dbl.

Dominique is an adept individual who is able to take on any task in the field of deafblindness, from hands on education to management, with children or adults. A current example of her expertise and continuous interest in the field of deafblindness was her involvement in the 8th Dbl European conference despite the fact that she had recently retired. Not to take retirement too seriously, Dominique has enrolled to take the Masters Degree in Communication and Congenital Deafblindness from the University of Groningen, Netherlands.

Deafblind International is so proud to present the Distinguished Service Award to Marlene Daelman.

Marlene is described as someone with a very humble attitude who has deep concern for individuals who are deafblind, their families and the staff.

She has spent all her professional life as a consultant with KMPI Spermalie in Brügge, Belgium working with children with multiple disabilities including children who are deafblind. Her main concern has always been to develop high quality services for the children and to support the families and her professional partners. In 2003 Marlene finished her PhD degree at the University in Leuven focusing on communication with children with multiple disabilities.

A parent she has worked with said that Marlene had a listening ear and was a very human advisor. She helped ease their worst nightmares and convinced them that the professionals were there to assist them with their daughter and that she was there for the long journey with their daughter.

In order to provide the very best programs for these children, Marlene reached out to colleagues to develop her expertise. More than 20 years ago she saw the need for a communication working group and together with four international colleagues established Dbl's Communication Network. Today the field benefits from her insight into the need for a research oriented committee. Marlene has had significant input on the production of the four books published on communication and congenital deafblindness. These publications are used internationally to assist professionals in providing appropriate communication strategies.

Further to this work, she was also a vital member of the team who developed the content for the master's degree program at the University of Groningen in the Netherlands. She continues to be a greatly appreciated lecturer and supervisor of this program.

## **Secretariat News**

### **Meetings**

In August 2013, the Dbl Board and Management Committee met in Lille France for the annual meetings. There was representation from 16 countries and with the diverse group we collaborated on the work of the strategic plan and set goals for the next few years. We are extremely fortunate to have the support of the corporate organisations on the Board who make it possible for these leaders in their field to guide the future direction of Dbl. We take this opportunity to thank Dominique Spriet and Valérie Taggiasco for their invaluable support in the lead up to the meetings.

## **Conferences**

### **DbI European Conference 2013**

The 8th DbI European Conference in Lille was a wonderful conference with an innovative program generating much discussion amongst old and new friends. We congratulate the organisers for running the event so professionally and thank the beautiful city of Lille for hosting all the delegates.

### **DbI World Conference 2015**

James Thornberry and Cristiana Salomie from Sense International made a presentation to the DbI Board in Lille outlining the progress they have made so far in organising the 16th DbI World Conference on Deafblindness. The conference will take place in Bucharest, Romania in the last week of May 2015. We congratulate them for taking on this project with such enthusiasm and look forward to supporting them in the lead up to the conference. We will keep members informed of conference announcements via email and will keep the DbI website up to date with any conference news.

### **DbI European Conference 2017**

During the conference in Lille we were delighted to announce that the Center for Deafblindness and Hearing Loss in Denmark has been selected to host the DbI European Conference in Aalborg, Denmark on the proposed dates of 5th – 9th September 2017.

### **DbI World Conference 2019**

In February 2014, we will be calling for Expressions of Interest (EOI) to host the DbI World Conference 2019. If you think your organisation, or a group of organisations would be interested in hosting the conference, please watch out for the EOI and submit an application within the timeframe. If you have any questions about hosting a DbI conference, please contact the secretariat and we will be happy to assist.

## **Membership**

During the Board meeting in Lille, it was decided that we would trial a one off promotional offer to invite new Individual members to join DbI for 5 Euros for a 1 year period. Those members will receive an electronic copy of the DbI Review and member news via email. We were overwhelmed by the response and welcomed over 50 new members from Australia, Belgium, Brazil, Bulgaria, Canada, France, Greece, Italy, New Zealand, Norway, Romania, Russia, The Netherlands, UK and USA. DbI recognises that the success it achieves worldwide greatly depends upon the support of its individual and corporate members to promote awareness and services. Thank you to the many members who have renewed their membership to DbI this year.

If you know of an organization who should be a member of Dbl we would be happy to send them a letter of invitation. Please pass on any suggestions to [secretariat@deafblindinternational.org](mailto:secretariat@deafblindinternational.org).

### **Change of Personnel in the Dbl Secretariat**

Due to growth and changes at Senses Australia, Elvira Edwards' role as General Manager of Services has expanded and to concentrate on the growing services and the many changes that will occur over the next few years in Australia she has had to relinquish her role as Secretary of Dbl. We welcome Matthew Wittorff as the new Secretary of Dbl and look forward to continuing to host the Dbl Secretariat.

### **Keeping in Touch**

We want to hear from you! Information sharing is essential to Dbl and is what keeps the organization strong and current. If you have information you want to share with others or if you're looking for a contact in a faraway place, please send us an email and we can work together to find a solution.

Elvira Edwards, Matthew Wittorff and Bronte Pyett  
Dbl Secretariat  
Proudly hosted by Senses Australia

### **A change in personnel within the Dbl Secretariat**

Senses Australia has been proud to host the Dbl Secretariat since 2008. I have enjoyed fulfilling the role of Dbl Secretary and am grateful for all that I have learned during that time and all the friends I have made. Due to growth and changes at Senses Australia, my role as General Manager of Services has expanded and I have had to relinquish my role as Secretary of Dbl to enable me to concentrate on our growing services and the many changes that will occur over the next few years in Australia. However I am delighted to have the opportunity to remain actively involved as the Senses Australia representative on the Board of Dbl.

Matthew Wittorff officially took over as Dbl Secretary on 18th November 2013. Matthew is the Manager Deafblind Services at Senses Australia and brings with him extensive knowledge and experience. Matthew and I are keen to ensure that the transition is as seamless as possible and we will work hard to facilitate this.

I am confident Matthew will fulfil the role of Secretary very well and I look forward to staying in touch with everyone in Dbl in the future.

Elvira Edwards.

## **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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William Green  
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## **Board Observers**

DbI's partner organizations, ICEVI and WFDB have observer status on the DbI Board:

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