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Review



Therapy at Maják

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

DbI Review appears twice yearly, the two editions are dated January-June and July-December.

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 and drawings are welcome; they will be copied and returned.

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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Cover: Music therapy at Maják, Slovakia

A message from the president

Dear friends and colleagues,

It's winter here in the northern hemisphere and, as I write, the snow is falling! Our colleagues who run the Secretariat in Australia are ready to spend time on the beach with temperatures soaring into the high 30 degrees. Wherever you are and whatever the weather I send you the compliments of the season!

In the autumn the DbI conference was held here in Italy, and not far from the Lega del Filo d'Oro – on the coast in Senigallia. It was a moment of considerable pride for me and my colleagues and an event that welcomed 450 people from 40 countries. There was a programme involving 120 sessions, including plenaries and workshops, and we enjoyed a number of beautiful historical settings to achieve this. We had a lot of positive feedback and will make sure the problems people reported will be taken account of and used in organisational learning.

After hosting such a high profile event we feel that we are even closer to the national recognition of deafblindness.

I had the great pleasure to attend the WFDB event in Uganda and to strengthen our bond of partnership. There is a full report of the meeting on page 44.



We are conscious of the great progress that ICEVI is making with the Education for All initiative and know we have an opportunity to add to this campaign. Our Vice President, Bernadette Kappan has attended the recent meeting of the Global task Force and we will hear more of this next time. Larry Campbell writes for us on page 33 and I urge you to consider his request for contact.

I had the very great honour to be in the Czech Republic last month to witness an agreement that pledges support for the development of a service for young adults. The Family Association has been lobbying for this style of development for some years. Now things will start in 2012. A great achievement.

We are already beginning to think about the future – and to 2011 when we will meet in Brazil. The

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committee that works on nominations will be starting its work shortly. Work on the Conference is moving quickly and I will be travelling to

Sao Paulo, with ManCom, to meet the team again
Thank you all.

William

EDITORIAL

Dear Friends

We celebrate success in this issue!

A great story of personal endeavour and plain hard work is the backdrop to our cover story about the development of the first specialist service for adults in Slovakia. Parents and professionals have worked together, with young people, to create a way of living that treats each deafblind person as an individual with a future.

Another young person, in Norway, is certainly living his life on the edge – with a white water rafting trip that involved hiking and camping. Experiencing the thrill-including the fear and anticipation of the next torrent of white water – made this holiday “5 star” for this young extrovert and his friend. Keeping the balance between safety and experience is a continual tension – happily achieved with great planning this time.

It’s very good to have a piece from Jan van Dijk and Kathy Nelson. They are writing about the field of neurobiology and what it can contribute to our work with deafblind people. This well researched, and compelling, article will provide a stimulus for us all to learn more. And a new DVD will be out soon to support practice in this area.

I have been fortunate to visit Bangladesh. It’s a fascinating country with warm, welcoming people but presents a very challenging environment for disabled people. So it’s great to read about the Sadat and Rizwan and developments there.

I did say at the start that we are celebrating... and formal congratulations and honours have been recorded later in this magazine. I would like to say, as I hand this role on to someone new, that it’s been a great pleasure to have been in contact with so many people world wide over the time I have edited the magazine! It has confirmed my long held view that the only way forward is by sharing our ideas and learning from each other. Your participation has made a real difference.

As you know already, the intention is to strengthen the way Dbl provides information and we are doing that by investing in the website and other “e” ways of working. We have already started but there is still a lot to do. It’s a very exciting time for Dbl and we can’t do it without your continued support!

Good wishes.

Eileen

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“Maják”

Henrieta Hajdeckerova, Director of the first home for a group of deafblind people in Slovakia, describes the challenges of making this dream become a reality...



Juraj painting

“ I’d like to say the important thing by a few words about the first, and so far the only, facility of its kind in Slovakia and about our legislative support.

Maják is the first facility for deafblind adults in Slovakia. The name Maják means ‘Lighthouse’ and symbolises the hope that was missing in the lives of deafblind people. The Maják project was started in 2003 upon

an initiative of parents and specialists in the field of deafblindness and the home and services opened in 2007.

Deafblindness, as a special type of impairment, had not been considered in Slovakia until then – it officially had not existed at all. On the basis of widespread and intensive lobbying from specialists, the term “deafblindness” entered the legislation for the first time this year. The new law

on social services has come with a new type of facility, “a specialised facility, in which social services are provided to a person with an impairment – deafblindness”.

This new type of social service has brought an individual approach to the client. The new law has also brought a new way financing, which takes into consideration the extent of a citizen’s impairment. For example, each client in the facility receives a different financial subsidy, in contrast with the previous law, by which each client, irrespective of the extent of his or her

“The name Maják means ‘Lighthouse’ and symbolises the hope that was missing in the lives of deafblind people”

impairment, received the same financial package.

But despite those improvements in the law, which we consider to be a great success and a step forward in the field of deafblindness in Slovakia, not-for-profit and non-governmental organisations, such as our Maják, will not feel those changes to such an extent as state-run organisations. Not-for-profit organisations are still at a great disadvantage when compared to state organisations. They are perceived as private facilities, which may, but do not have to, exist. Neither the state, nor the self-governing region provide guarantees for the preservation of the existence of such facilities. So at "Maják" we are working hard to spread the word about the work we do!"

Living at Maják!

Janka Sarisska tells us more...

The start of 2007 became significant for young deafblind people and their parents in Slovakia. On 2 January 2007, parents brought their deafblind adult children to Maják and gave them an opportunity to live their own full-valued life, in which each individual is recognized as a unique personality. It was a huge



A religious painting

event for the deafblind people, their parents, siblings and specialists.

In the past all 18 year old deafblind young people, after completion of the elementary school, either stayed at home or were in facilities for mentally disabled, without receiving the correct professional approach. In institutions for the mentally disabled, they did not have their own structured daily programmes; they did not get an individual approach, no adequate communication was used, and therefore they didn't receive information either. When they were at home, parents were unable to secure for them a whole-day programme that would stimulate them and move give them a chance to make

choices and have fun and success. Without the chance to expand their vocabulary in sign language and the young people returned to their previous negative expressions and stereotypes, and forgot some of their skills. Deafblind people need life-long education. They need their structured programmes, contact with their surroundings, communication and continual stimulation in order to keep developing. If that is interrupted, regression is the outcome.

After a three-year pause, the start of the Maják was not easy. The problem was also in the fact that we had a young team of workers in Maják. Before the opening of the group home they were trained for the work with



A harmony of colours

deafblind people. But they didn't have any practical experience in the work with deafblind people and they had difficulties in coping with problematic situations with residents. Some of them wanted to leave after a month – feeling they could not succeed. We worked hard to overcome this.

For a whole year, we worked with the clients' on any negative reactions and built a system that was based around their personal needs and interests. We created

“ A great plus of the project has been that we have put such activities into the hands of professionals ”

regular daily programmes; we used appropriate communication and did various activities. All this contributed to the fact that the first beneficial results showed after a year.

The second year of the operation was very significant. We wrote a project that included various leisure time activities, focused on the development of our clients' personalities.

Deafblind clients do not realise what the concept of “leisure” is, so we organised lots of “taster” activities for them and believed that if the planned activities were offered they would realise they were some pleasant ones! Then they would enjoy them and look forward to being able to do them again.

The activities we chose – riding, art therapy, music therapy, bowling, dog-therapy and swimming we chosen to:

- support all-round development of an individual's personality;
- create and influence social relations, social interaction and communication;
- support health, physical development and a healthy lifestyle;
- act effectively as prevention against the occurrence of pathological phenomena;

By participating in the activities, the clients gained:

- a feeling that they have achieved certain performance;
- opportunities to improve their body control;
- physical and mental challenges;
- strengthening of their self-confidence;
- an opportunity to discover a certain talent in themselves;
- an opportunity to achieve self-fulfilment;

The main specific feature of deafblind adults' enjoying their leisure time is that they need assistance and supervision – and from people who really understand their own particular leisure activity.

A great plus of the project has been that we have put such activities into the hands of professionals.

The art therapy has been done by a fine artist, the horse-riding by an equine expert, the work with dogs by a trained canine therapist, the music therapy by an experienced therapist with many years of experience of work with multiply-impaired young people.

Through trying out such therapies and activities, we wanted to get our deafblind residents to the point where they can make their individual choices based on the interest and appeal they found in the activities.



Juraj puts a little house or a young woman into almost every painting

So how did we get on with this leisure programme?

Art therapy – despite the fact the art therapist didn't have any knowledge of deafblindness and he did not have any command of communication, he engaged the attention and interest of some clients on the first day! In the second meeting, they started to paint spontaneously, and so it was every day after that! The art therapist became not just their art teacher, but also their friend.

Those who work at a higher level and have developed their communication know how to choose a specific topic, express their dreams and desires in pictures.

I'll show an example. Juraj and Martin are young people, who grew up in an orphanage. They didn't know their parents and they didn't have the experience of living in a real family. In their hearts there is a hidden desire to have their own home and a

close and loving person in it. That can be seen in their paintings. Juraj puts a little house or a young woman into almost every painting. Martin, in turn, paints roads, which gives us the impression that he is constantly looking for what he is missing. Peter's drawings reflect his sense for the detail. Pavel is a devout young man and, in his paintings, he expresses his relationship with the religion. He depicts the crucified Christ or Virgin

Mary. He started drawing for the first time when he was 40 under the leadership of the art therapist. He had never held a paintbrush in his hand before.

Clients who are at a lower level have fascinating artistic works, though there's nothing specific in their pictures. It is just a harmony of colours.

Already the first art therapy meetings have shown that such an activity calms the clients. I asked the art

Martin paints roads





therapist to tell his experience with his deafblind clients and what he thought about their mutual cooperation.

“Every time I work with new clients is a new start, a new challenge. One never knows in advance how the work will develop and what the results will be. It is very important to establish a working, human and artistic relationship with clients and to try to create in that spirit. When I open my heart, I can expect that also the client will adequately open himself, and then the connection occurs – a road on which we can create together, spend time and achieve some results. Each meeting is different and the results are different as well. What we have created in Maják encourages me and inspires to meet future challenges. In conclusion:

No matter how a person is impaired, he or she is worthy of attention”

Horse riding

Horse riding induces positive changes in the clients. The training on a horse improves their coordination of movements, body posture, and sense for balance. During the ride, the client corrects balance, controls the horse by touch or by the bit, and thus increases his confidence and also self-confidence. By tapping the horse and hugging it, s/he expresses a relationship and thankfulness and joy.

We go horse riding once a week. The clients look forward to that activity and keep asking “Are we going to

go horse-riding on Tuesday?” After horse riding, the young people return joyful and satisfied!

Dog-therapy

Each client experienced the dog-therapy individually. Some of them expressed anxiousness, fear and rejection. They gradually become friends and it was turned into play with a dog. But there were also clients who played with them, took them into their laps and were joyful. The therapist worked with them systematically and individually. She taught the clients to give commands to dogs and they reacted to them. There was very good cooperation with them. Then they were rewarded with food, a toy or stroking. Such situations encouraged the clients a lot and gave them self-confidence.

Music therapy

The non-governmental organisation Mayak cooperates with a music therapist, who started working with our clients when she visited the school for deafblind children. She wanted to achieve the clients' independence in playing rhythmic musical instruments. When the clients





managed individual games with the music therapist's assistance, everything moved spontaneously to group music-therapy sessions.

Bowling

Three clients started bowling under the leadership of a coach. This activity has absorbed them a lot. They go out for training once a week and they have taken part in

a competition with sight-impaired sportsmen and women.

Swimming

Swimming is a very popular activity for our clients. We make it possible for them to do that activity throughout the year. Swimming brings them joy, satisfaction and relaxation.

These activities have

allowed the clients to obtain some new skills and to develop cognitive functions, social skills and emotional living.

We have managed to use such skills and capabilities for an integrated theatre performance with students of social work under the leadership of the art therapist and the music therapist.

The cooperation with the art and music therapists has led to the clients' ability to fulfil their leisure time with artistic and music activities. Dog-therapy, swimming, horse riding and bowling also became the favourite activities for leisure. Our goal is to achieve our clients' moving from therapy and interest activities to feelings of self-satisfaction and self-fulfilment. Currently we are at the stage of a transition from therapies to a conscious interest in these activities – or new ones they might discover!

Lessons learned from Neurobiology

Jan van Dijk¹ and Catherine Nelson²

The Deafblind International (DbI) Conferences have been very important forums in which to learn and evaluate state-of-the-art theory and practice regarding the education of persons with deafblindness. Initially, the focus of the conferences was on practical issues of teaching congenitally deafblind children, but over the years, a broader perspective has developed. This perspective was reflected in the inclusion of relevant information from other disciplines. For example, the field of genetics informed

“It is our belief that recent research studies on stress can shed some light on very important issues of behaviour and learning of persons with deafblindness”

us about specific syndromes, audiology told us about new testing methods and useful prostheses, and ophthalmology, about early intervention to prevent the worsening of a child's eyesight. Clinical psychology and psychiatry informed us about psychiatric problems and challenging behaviours experienced by persons who are deafblind and occupational therapy informed us about sensory integration. All were welcomed as we strove to meet the medical, social, psychological, and educational needs of deafblind

persons. It is now time to introduce another field; neurobiology.

There is general agreement that children who are now diagnosed as being deafblind are often very neurologically involved. Many of the children also have severe orthopaedic problems, some are very medically fragile, and some, exhibit undesirable behaviours (e.g., self-injurious behaviours, aggressive outbursts). A recent study by Fellinger et al., in 2009 found that over 20% of persons with severe intellectual disability in an institution in Austria met the diagnostic classification for being deafblind. Yet only a small percentage of the individuals were so identified prior to the research. In this brief article, we would like to highlight some of the new research that utilizes neurobiology and has the potential to help the population of individuals with multiple disabilities in addition to deafblindness.

It is our belief that recent research studies on stress can shed some light on very important issues of behaviour and learning of persons with deafblindness. Scientific methods have been developed to determine a person's stress level through measuring the hormone, cortisol. As has been demonstrated, prolonged periods of stress are devastating for the neurological growth of the child and the development of his social behaviour. (Lee, Ogle, & Sapolsky, 2002; Shonkoff & Phillips, 2000; Van Dijk 1999). In a recent study using cortisol levels as a measure, Sterkenburg (2008) demonstrated that a combination of relational therapy (attachment) and

techniques of behavioural support reduced unfavourable stress levels in a sample of multiple disabled blind children and adolescents and thus, positively changed their behaviour. Similar findings have been reported in children in foster care children (Dozier 2006). There is considerable evidence that many persons with concurrent disabilities of hearing and sight experience much anxiety which may express itself in inappropriate behaviour. It has been found that this is due to a dysregulation of the amygdala, an organ located deep within the brain. It is an important structure in fear conditioning and the recognition of potential threats. The amygdala has many connections with other brain areas and so a threatening experience with one person (e.g., abuse) can generalize to other persons. Even when such fearful persons are approached in a gentle way, there may be a substantial emotional reaction. This behaviour can often be observed in persons with deafblindness but it has been found that the introduction of an intensive system of reinforcement can lower the fear reaction significantly (Arden & Linford 2009).

Another example of the use of neurobiology is seen in the field of Autism. The field of deafblindness is increasingly becoming aware of the possible relationship between children with deafblindness and Autism Spectrum Disorder. The discovery of mirror neurons is very important to understanding the role that both hearing and sight play in development. The mirror neuron system (MNS) mediates emotional recognition within the observer who feels a similar

“It seems that the intensive relationship between caregiver and the child triggers a system in the human brain which leads to a feeling of happiness and joy in both partners”

emotional state to the one being observed (Van der Gaag, et al., 2007). This matching system is very important as we understand and correctly interpret facial expressions. This understanding can be considered the basis for social development.

The above are just a few examples of recent findings that are extremely important for researchers and practitioners who work with individuals who are deafblind. Such findings demonstrate that our behaviour is very much related to processes in our brain. In her keynote address to the 2009 Dbi conference in Italy, Professor Marlene Janssen mentioned that quality of life is a

concept that should be explored in depth. We agree with this, but would like to add that this research should focus not only on cortical functions, but also examine the fundamental role our emotional brain plays in the well being of individuals who are deafblind. As we examine the emotional brain, it is also incumbent upon us to look at relationships. It seems that the intensive relationship between caregiver and the child triggers a system in the human brain which leads to a feeling of happiness and joy in both partners. This is the phenomenon of resonance that has been the focus of much of our early research.

It is true that for many practitioners, research findings are not easily accessible, therefore we have decided to develop an instructional DVD with many clips of children with serious cognitive impairments but who have still a vast repertoire of feelings and emotions. This production will be called Let's talk Limbic. The role of the emotional brain in education and care for persons with multiple sensory impairment. We are working on this project with a multi-disciplinary team of professionals (Drs. Nelson, Fellingner, De Kort, Van Dijk & Van Dijk). In order to keep our colleagues up to date on a number of exciting developments in the adjacent fields, there will be a web site opened during 2010 with an advisory board comprised of several professionals in our field: Drs. Silberman, Bruce, Janssen, Nelson, and De Kort. We will give you further information in the next Dbi Review.

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Air, Fire and WATER!!

With thanks to Anne Nafstad and "Ostlendingen" for this story

For deafblind Tormod Johnsgråd in Sømådal in Engerdal and his Danish friend Peter Hangrød this past year had a dream summer...

It all happened thanks to Marte Undseth Hagen, a 25 year old medical student from Elverum. Fearlessly, (but with careful preparation) she took the disabled classmates on the toughest tour – one that would take anyone's breath away! It was with greatest of pleasure that mates, Tormod and Peter took to the outdoor life and tackled everything from rough, river-rafting to the mining tours.

Marte wished, so fervently,

“For her it was brilliant to see how they enjoyed themselves – even though they had to be rescued several times!”

that Peter and Tormod would get a fantastic summer with outdoor activities as the main ingredient that she went ahead and planned together a 14-day holiday, obtained sponsors and good helpers so that wilderness programme

could happen!

According to Marte even if they do not hear or see, the boys have a very well developed sense of "feel". For her it was brilliant to see how they enjoyed themselves – even though they had to be rescued several times! Their adventures were varied. One day they went white water rafting down the river Gløta which runs between the lakes. Tormod's brother Jonas joined them for this very tough trip. It was simply amazing. Tormod and Peter threw themselves into the water to experience the feel of the cold water – it was "wicked cool"! Tormod was fearless into the foaming

White water!





Rapids

water and his brother Jonas brought him safely back into the canoe again. This was repeated several times, to Tormods great joy!

During a canoe paddle trip on Femunden they had beautiful weather. Tormod and Peter sat with their hand in the water for the whole trip and felt the power of the river. Peter smiled all day. The time had gone so quickly

and he thanked the guide for their very special support!

The pictures tell it all!

These two young men have experienced the steep and uneven footways inside the mine with a cold damp air on their faces, and hiked the challenging terrain. They have tackled white water rapids, eaten charcoal blackened sausages and bathed in both heated water and ice cold



Marte Undseth Hagen

mountain streams!

Marte made very comprehensive preparation and thanks everyone who helped make it come true!



Bath and bubbles



Campfire



On the water



All together

SuperSibs – The Australian Experience

Karen Wickham, Social Worker at Senses Foundation in Perth, tells us more about the programme they have developed based on “Sibshop”...

In 2006 Senses Foundation established the “Super Sibs Program” to support siblings of children who are deafblind. The program is loosely based on the “Sib Shop” model with adaptations to incorporate the unique issues that can be related to having siblings who are deafblind. The Sibshop model was developed by Don Meyer of the Sibling Support Project and has been implemented worldwide. Mr Meyer offers this description of Sibshops:

Sibshops are lively, pedal to the metal celebrations of the many contributions made by brothers and sisters of kids with special needs. Sibshops acknowledge that being the brother or sister of a person with a disability is for some a good thing, others not so good thing, and for many, somewhere in between. They reflect a belief that brothers and sisters have much to offer one another – if they are given a chance. The Sibshop model mixes information and discussion activities with new games (designed to be unique, offbeat, and appealing to a wide ability range). Sibshops: Workshops for Siblings of Children with Special Needs – Donald J. Meyer & Patricia F. Vadasy

Siblings of children who are deafblind can experience both good and bad feelings about their brother or sister. Basically, siblings of kids with disabilities feel many of the same emotions and concerns that their parents can feel. However, because the relationship between siblings and their parents, as well as each other, is different

from a parental relationship, they also have experiences and concerns different from others.

Brothers and sisters of children with a disability routinely face problems that are not experienced by other children and siblings generally have far fewer opportunities for peer support and education, compared to their parents. Common themes that siblings of children who are deafblind may experience are: feeling isolated, pressure to achieve, concerns about their siblings future, over-identification and fear that they will develop a disability, increased responsibilities, bullying, conflicting feelings of guilt, fear, anger, resentment, envy, loss, embarrassment and confusion. Brothers and sisters of children who are deafblind have a lot to teach one another, if they are given the chance. It is healing to be involved with others who are “in the same boat” and who understand better than anyone what it is like to be the sibling of a brother and sister who is deafblind.

“SuperSibs” seeks to provide siblings of children who are deafblind with opportunities for peer support and education, through activities designed to accomplish the following:

“Super Sibs” Goals are to:

- meet other siblings in an relaxed and supportive setting
- provide siblings with opportunities to discuss common

joys and concerns with other siblings

- provide siblings with opportunities to learn how others handle situations commonly experienced by siblings of children with disabilities
- provide siblings with opportunities to learn more about the implications of their brothers and sisters unique disability
- enhance understanding of the importance of communication between siblings and their families
- have fun in a safe and non-judgemental environment
- provide parents and other professionals with opportunities to learn more about the unique concerns and opportunities frequently experienced by sibling of children who are deafblind.

Value and Benefits of “SuperSibs”:

The “SuperSibs Program” has been designed and developed to provide a safe and supportive environment for siblings to share their feelings, concerns, questions and problems. The group creates an atmosphere for positive change and adaptation whilst reducing sibling’s senses of isolation and creating opportunities for new friendships. “SuperSibs” encourages the growth of more positive attitudes and understanding toward siblings who are deafblind along with an increased sensitivity to their brother



Jacob (deafblind) towing his twin Zachary – aged 12

or sister's unique disability. The program offers siblings a broad array of solutions and strategies from which to choose to cope with their own individual challenges living with a sibling who is deafblind. The group celebrates and maximises the unique opportunities that arise from having a sibling who is deafblind and siblings gain a sense of their own uniqueness knowing that the group had been developed just for them.

Fun and support

"SuperSibs" to date, has run many successful programs including: workshops based on the Sibshop Model –incorporating opportunities for siblings to meet other brothers and sisters of children who are deafblind, lots of games, learning opportunities, cooking and craft activities along with lots of laughs and fun!!!

SuperSibs has conducted discussion and peer support forums dedicated to the good and not so good parts of having a sibling that is deafblind – one example is the "Sound Off" game – giving siblings the opportunity to tell just one thing that is good, bad or so-so about having a sibling that

is deafblind.

Dear Aunt Blabby is another firm favourite – letters to Aunt Blabby are placed in individual envelopes – each letter details a problem that a sibling may be experiencing i.e. bullying, embarrassment, sadness, the group is then invited to draw on their experience and reply to the letter with suggestions of strategies that might help.

"My Special Dream" gives the opportunity to siblings to write or draw about their own special dream for their sibling – the groups favourite so far has been "I wish my brother could be a racing car driver!!!".

SuperSibs has also held workshops to help siblings to learn more about the unique communication needs of their sibling who is deafblind – "Helping Hands" provided lessons in basic Auslan and discussions about the use of tactile signs. Siblings are encouraged to learn and embrace their siblings' unique communication methods to strengthen their own relationships.

Senses Foundation has also hosted several family days in support of our siblings. Respite staff are provided on the day

to look after the child who is deafblind giving the opportunity for siblings to have one on one time with their parents in a relaxed and fun environment. The opportunity for a family outing can be limited when a family is caring for a child who is deafblind. "SuperSibs" provides the forum where families can relax and enjoy all their children.



"SuperSibs" workshop

So it works for us...

Many of our earliest and most memorable life lessons in sharing, trust, patience, tolerance, jealousy and frustrations have been learned through experiences with brothers and sisters. We should expect no less from siblings who have a brother or sister who is deafblind. In fact we need to acknowledge the sometimes subtle and hidden complexities a deafblind child brings to the relationship with siblings. Siblings provide the first and possibly the most interconnected relationships children will experience and we cannot disregard the incredible resource siblings of children who are deafblind represent – the art is in the balance.

Senses Foundation continues to work towards raising awareness of the issues that siblings can face reflecting our commitment to the family member most likely to have the longest-lasting relationship with the child that is deafblind.



Acquired Deafblindness Network

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Rubella Network

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Siblings Network

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Usher Study Group

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Acquired Deafblindness Network

Ges Roulstone reports

The co-ordinating group of ADBN held its Autumn meeting in The Netherlands on the weekend of 10th and 11th October.

The group agreed the 2nd announcement for the next ADBN conference to take place in Aalborg Denmark on 29th September 2010 to 3rd October 2010 and undertook further work on the programme of plenary speakers.

Papers are now invited for 24 workshops which form an ever greater part of each conference programme. The group will meet on March 20 – 21st 2010 in Denmark to finalise the plenary and workshop programme.

In the meantime, because of changes to the working and personal circumstances of two of the members of the Co-ordinating group, two vacancies now exist and ADBN Co-ordinating group is keen to hear from suitably qualified professionals who would like to assist in the running of

this very successful and influential network. Candidates should possess the following:

- A suitable background in practice or management of services for those with acquired deafblindness
- Fluency in English
- The ability to travel to meetings in different European cities twice yearly
- Time and energy to devote to real work towards continuing ADBN's successful programme of bi-annual conferences

Please write in the first instance to Chair of ADBN, Ges Roulstone at ges.roulstone@sense.org.uk



Call for papers – see page 22

Congenital Deafblind Network



Knut Johansen and Dominique Spriet report

A very productive meeting was held in Senigallia – 9 people attended along with the 5 regular members.

After a presentation of the work done, including the struggling and difficulties the network had encountered we came to the following conclusions:

1. In the past our work was focused on the congenital deafblind adults. However, it is evident that the condition of being congenitally deafblind is not linked to age. So we wish to be able to address questions concerning all the persons affected by congenital deafblindness. So we have named the network the Congenital Deafblind Network (CDbN).

2. The links to other networks are strong and important: communication, siblings, art and leisure, tactile communication, rubella, charge syndrome etc. We learn a lot from them.

The shape and model adopted by those “unique question” centered networks cannot be ours, as

we have to address many other themes: such as sexuality and relationships, staff development, daily living skills, locomotion and mobility etc. We are concerned by the person as a WHOLE.

So we wish to be able to put up on Dbl’s website a structure centered network for hands-on people working directly with congenitally deafblind persons, to be able to share experiences and recommendations – not for solutions, but for sharing ideas. A mailing list is on the way and a frame on “how and why” to share things is going to be elaborated. Answering and sharing those questions might include the sharing of documents, experiences already existing, all sorts of information etc.

3. In the same line: being concerned about the person as a WHOLE. This network wishes in some ways to be the voice of the congenital deafblind persons within Dbl, to speak for those who cannot do it by themselves directly.

We wish to put up a document

that could have the Dbl logo, presenting

- The UN declaration
- The European declaration
- The Dbl definition of deafblindness with its different aspects congenital, acquired

This document could be completed by recommendations from the different networks concerning the congenital deafblind population.

Such a document could then be used in the different countries with the local cultural, economical and political adjustments to support the needs of the congenitally deafblind person.

I wish to thank each of the participants for an enriching morning and for the prompting they promised to do, in order to take this network forward.

Dominique Spriet,
Co-ordinator of CDbN
sprietd@aftam.asso.fr



CHARGE Network Beatrice Zoppi reports

The Charge network met in

Senigallia. Three presentations were given by Steve Rose (UK); Andrea Scheele

(Germany) and Gail Deuce (UK)

Professionals from different countries attended, committed to supporting children and young people with CHARGE Syndrome and their families.

A desire was expressed to develop an interactive site linked to the current DBI website. It was agreed that there is a need to identify a number of clear statements to clarify what the group is about.

A task group was identified and they agree action points as well as this report for DBI Review to promote increasing membership in this Network.

Please, if you are interested to share ideas about how to provide

a better support to this population contact us.

The task group is:

- Martha Majors (USA)
- Andrea Scheele (Germany)
- Alison McWilliams (Australia)
- Beatrice Zoppi (Argentina)
- Gail Deuce (UK)

Beatrice Zoppi, Argentina,
November 2009.
(beazoppi@yahoo.com.ar).

Siblings Network

Sabine Kersten reports

The Dbl European conference in Italy was very success and may prove to be a turning point for the Siblings Network. During this conference I had the opportunity to give a plenary lecture about brothers and sisters and the impact deafblindness has on their lives. I spoke about the relationship between brothers and sisters in general, about the positive and negative consequences. I also talked about the impact having a brother or sister with special needs has on the lives of the siblings, about their need for information and about the future when parents can no longer take care and brothers and sisters have to take that responsibility.

It made a lot of people (parents and professionals working in the field) aware of the special situation in which we, as siblings, grow up.

Network morning

We also had a network morning, during which we had the opportunity to present a programme to interested delegates.

In Italy, there is a group of adult siblings who meet regularly to talk about their experiences and to support each other. We had an interview with three of them. They told us that joining the group was not easy in the beginning, but as they came to know each other they felt this contact really helped them to deal with some of the issues they came across.

Then there were people working for various organisations telling us about services they offer to siblings. There are some organisations who do offer support, mainly by offering a weekend filled with fun activities to siblings.

A small group of people (parents and professionals) came to our morning. With them we had a discussion about services that could be offered to siblings of different age groups.

As a result of all this, we are now thinking of activities we can plan in the coming year(s).

As mentioned before, siblings do have a need for information. Therefore we will focus on this need by developing information on



deafblindness and siblings issues for children which we be age appropriate.

From 27 July – 1 August 2010, the family conference “Listen to me” will take place in Olocouc in the Czech Republic. This will be a wonderful opportunity to meet families and share experiences. And we will try to be present there as well.

I am looking forward to your comments or ideas so we can futher develop the Siblings Network.

Looking forward to hearing from you!

Sabine Kersten

siblingsnetwork@gmx.net

DATE FOR YOUR DIARY ...

Listen to me!

Family Conference

Will be held in Olocouc, Czech Republic

27 July – 1st August 2010

Usher Study Group

Marylin Kilsby reports

About twenty-five people attended this Network Morning, including several people with Usher as well as professionals from various European countries. After an introduction on the various Types of Usher led by my colleague, Tamsin Wengraf and a summary of advances in accessible computer and mobile phone technology, we welcomed Kerstin Möller from Sweden, who presented her own research on the sociological side of Usher. Kerstin then metamorphosed into Professor Claes Möller, also from Sweden, who was unable to join us. "Claes" gave us information about the latest medical research and treatments for RP which may be possible in the not too distant future.

We then welcomed Riitta Lahtinen from Finland, who gave a fascinating introduction to social-haptic communication within the family. She and her partner, Russ Palmer, demonstrated what haptic communication is about and how it can be used to inform deafblind people about their environment as well as its role in

general communication. Social-haptic communication is becoming ever more widespread because of its usefulness as a communication tool for people with a dual sensory loss.

“Francesco gave a moving account of his life journey and stressed how important communication is to him.”

Finally, we had two contrasting presentations from Usher people themselves. Russ Palmer from the UK, who is a musician and music therapist, talked about the challenges and advantages of living with a cochlear implant. He described what it was like to have the cochlear implant and how it had helped him, especially in his musical career. Russ has brought out a new CD, "Warm Summer Days", which demonstrates his very pleasant singing voice as well as his



remarkable guitar playing.

Our other Usher presenter was Francesco from Italy. Francesco has Type 1 Usher and uses hands-on signing to communicate. He gave a moving account of his life journey and stressed how important communication is to him. Francesco is always cheerful and positive, a really good example of how life as a deafblind person does not need to be dull.

The Network Morning finished with a brief discussion (time had run away with us!) on the future of the Network and whether an e-group could be a way forward. The general impression was that an e-group would be a good idea, with a separate section for professionals as well as a general e-group.

We invited everyone at the group to the next full Usher Study Group, which will be held on 27 and 28 September 2010 as a pre-conference to the ADBN conference in Aalborg.

Marylin Kilsby

JOIN US...

if you would like to contribute or wish to join us for this special event

The Usher Study Group

27th and 28th September 2010

A pre-conference to ADBN

Conference in Aalborg Denmark

Rubella Network

Nancy O'Donnell reports



About 25 people participated in the Rubella Network meeting at the DBI European

conference in Senigallia, Italy, the morning of September 25th. This network is interested in the broad range of issues around rubella, including immunization, health, diagnosis and quality of life. It is open to anyone who is interested in this topic.

According to the World Health Organization (WHO), international immunization efforts are effectively reducing the incidence of rubella globally.

Linda Long from Scotland announced good news about the success of the MMR immunization program. A vaccine against measles, mumps and rubella was introduced into the childhood immunization program in 1998. Ninety-two percent of children in Scotland have received one dose of MMR by age 2, 95.6% by age 5. The positive outcome of high MMR uptake amongst children in Scotland is evidenced by the low incidence of rubella seen in Scottish communities and the fact that there has not been a baby born with congenital rubella (CRS) in Scotland in the 21st century. We are grateful to the many health professionals who continue to provide good information to families and support them to understand the potential consequences of infectious disease outbreaks amongst children.

However, Joff McGill of Sense, UK, reported that immunization

rates in the UK have been severely affected by the MMR/autism debate, despite the fact that there has been no credible evidence linking the vaccine to autism. The cumulative effect of this decline in immunization is that an estimated 3 million children in the UK have not been vaccinated for MMR! Sense supports MMR vaccination as the safest way to protect children. For more info on this issue, visit the Sense website www.sense.org.uk

Health Factors: Susannah Barnett of Sense UK reported on a study she is conducting which will focus on the health of people with CRS. The results of this study may help us to better understand the influence of a genetic predisposition to health concerns (such as diabetes) as opposed to those who develop illness or disease from CRS only.

Health Related Quality of Life of Mothers of Adults with CRS: Normadeane Armstrong reported on the results of her doctoral dissertation on this topic. It was the first time that mothers' health was studied in relation to caretaking for this population. It confirmed what moms already knew – that caring for a child with multiple needs can have a major impact on the mother's health. Hopefully, this study will lead to more research on the health of parents and caretakers and better supports for all.

Jude Nicholas and Evabritt Andreassen of Denmark are looking into many great questions: Do individuals with CRS have a high risk of developing dementia, especially those with intellectual disabilities?

How do we know if cognitive decline is related to CRS or to deaf-blindness in general? Many tests that are used to test dementia in the sighted hearing population are not normed to those who are deaf-blind. What do we know about structural changes in the brain? We need to do individual studies or assessment to find out what's going on, possibly using siblings for comparison.

For people with CRS, rubella is an infectious disease and the infection affected each person differently. How will assessments determine the amount of cognitive decline related to CRS? MRI can determine if there is an actual physical structural change in the brain, but this does not necessarily mean that it will have a direct effect on behavior or health. What is the effect of mental health issues, i.e. depression, on one's cognitive functioning? And finally, have we sufficiently studied the impact of excellent communication on the health status of those who are congenitally deaf-blind and aging? Stay tuned as we learn more about the results of these studies.

Nancy O'Donnell and the Helen Keller National Center (HKNC) continue to work with the Centers for Disease Control to collect blood samples for the biomarker study. They are trying to determine if there is a unique biomarker in the blood of adults with CRS and, if so, can that be used to develop a blood test to diagnose CRS in adults whose diagnosis is unknown? HKNC also continues to collect and analyze data on their 2004 survey. Results will be posted at www.hknc.org

European Deafblind Network (EDbN)

Ricard Lopez reports



During this year the EDbN has taken part in two great events, the Assembly of the

European Forum of Disability (EDF) and the 7th European Conference of Dbl in Senigallia (Italy).

The Assembly of the EDF took place in Athens. The most significant was the fight for the position of President between Yannis Vardakastanis, who is present holder, and Jean-Luc Simón. Yannis was re-elected.

The participation of the EDbN in Senigallia was managed by Lucy Drescher, Ursula Heinemann and Ricard López. It consisted of a session of information and discussion about:

1. Who we are, our goals etc and how we can all lobby/campaign/advocate together at a European level;
2. The status of recognition of deafblindness;
3. Work in Brussels and the progress of the proposed Equal Treatment Directive, to

Sergei Sorotkin



Grzegorz Kozowski thanks Dbl for its support

apply to disability, age, sexual orientation and religious believe. The aim was to make these areas equal to gender and race, as there are already directives aimed at tackling discrimination on these grounds.

4. UN Convention on the Rights of Disabled People (CRPD). Riku Virtanen spoke eloquently about his reflections on this subject.
5. The work of the Dbl Advocacy Group – an update
6. Listen 2 Me 5 in Olomouc

in the Czech Republic, 2010. The committee of the hosting Czech organization showed us the latest information about this family event.

The Session was very dynamic and had numerous interventions from the participants. Sergei Sorokin and Grzegorz Kozowski

were excellent contributors.

Recent News

Very recent news, at European level, was headlined "Historical EU decision to ratify the first international human rights treaty". On 26 November, the 27 Heads of States and Governments gathered at the European Council adopted a decision for the European Community to accede to the United Nations Convention on the Rights of Persons with Disabilities. This is the first time in the European Union history that the Community is going to accede to an international human rights treaty and a great signal to all EU Members States.

Finally, we announce the next edition of the electronic bulletin "Deafblind Europe" for which we ask collaborations and suggestions. We hope contributions from deafblind people, families, professionals, volunteers, etc.

Ricard Lopez, EDbN
rlopez@sordoceguera.com



The 8th Conference of the Acquired Deafblindness Network
29 September - 3 October 2010 in Aalborg Denmark.

Building Bridges - connecting people

Using this theme we will be exploring notions of developing relationships between people with deafblindness, families, friends and professionals. Bridges not only connect people but enable movement and development, independence and growth of potential.

Among the conference topics are dementia and deafblindness, haptic communications, practical use of ICF in deafblindness, relations in families with deafblindness, and much more.

The conference language will be English.

Call for Papers

The co-ordinating committee would like to invite people to submit abstracts for the open workshops that will take place during the seminar. How the workshops relate to the theme of the seminar should be made clear in the abstract.

The co-ordinating committee has agreed on criteria that will be applied to all submissions. All information on submitting and presenting a paper can be found at the conference website www.dbcent.dk/adbn2010.

Closing date for submission of papers: 26 February 2010.

Acquired Deafblindness Network

The Acquired Deafblindness Network is recognised by Deafblind International (DbI) and was established in 1989. Its aim is to create and support a network of people who are involved in the world of acquired deafblindness.



Pilot project to train communication guide use for Australians who are deafblind

Senses Foundation in Western Australia has received funds from the Disability Services Commission to run the country's first pilot project introducing communication guides for people who are deafblind. The grants will be used to provide special training for a group of communication guides and at least three hours' intervention each week for the 15 people with deafblindness selected to take part in the twelve-month trial. For more information, contact Senses Foundation (<http://www.senses.asn.au/>).

Computer training

South Australia's Royal Society for the Blind (RSB), in partnership with Dolphin (United Kingdom) and Quantum Technology (the Australian agents), are conducting a pilot project to evaluate the effectiveness of new Dolphin Guide software (www.dolphinuk.co.uk/products.asp?cat=9). This software is designed to enable a person who is blind or vision impaired, with little prior computer experience, to easily perform such activities as browse web pages; write letters; send emails; scan and listen to documents. Ten participants in this trial will receive training from the RSB's Adaptive Technology Department and will participate in a survey and complete evaluation questionnaires at the end of the pilot project. Each participant will also, compliments of Dolphin, be able to keep the Guide software, as well as a refurbished PC, printer and scanner from the RSB. Dr Celia Chen, from Flinders University in Adelaide, will provide a report on the effectiveness of this software for the participants.

2009 National Usher and Deafblindness Camp

Melbourne-based Able Australia Recreation Program and Victorian Usher and DeafBlind Club and the Vision and Hearing Support Club have hosted a camp from 20 to 22 November on Phillip Island in Victoria for people with deafblindness.

First commercial Braille wine labels in Australia

Fox Creek Wines has released the first braille wine bottle labels in Australia. Working closely with the Royal Society for the Blind they have designed and produced new back labels for their current vintages with braille and large print text. The first three wines with the braille and large print text back labels are the 2009 Shadow's Run Sauvignon Blanc, the 2008 Red Baron Shiraz and the Vixen Sparkling Red.

Universal access

Participants in a National Dialogue on Universal Design, convened by Australia's Federal Parliamentary Secretary for Disabilities unanimously agreed that more work was needed to make universally designed homes more available. They also unanimously agreed on the need to codify a national approach incorporating the value of universal design to the community; a definition and a set of principles of universal design; and what its features are in relation to housing. There is a need to work closely with industry and the community, including access to education and training. An aspirational goal is for all new homes to be of agreed universal design standards by 2020, with interim targets and earlier completion dates to be determined for some standards. A commitment was made to form a high-level working party to achieve substantial progress within six months. The media release and full statement are at <http://www.billshorten.fahcsia.gov.au/internet/billshorten.nsf>.

Launch of web captel trial

A new technology trial was officially launched by the Ambassador for Deafness Forum of Australia. The ACE Web Captioned Telephony (CapTel) trial will allow Australians affected by hearing loss to receive supporting phone captions, in real time, via the internet. While the technology has been available in the US for some time, this is the first chance Australians have had to use it. Web CapTel works with any type of phone. The important difference is its ability to display every word the caller says as they speak, in a similar manner to captioned television. The trial will involve more than 500 people over a two-year period. For more information, go to <http://www.aceinfo.net.au>

Australia



Mike Steer

Australia continued

Simply scripts

Although some DVDs have audio description, they are few and far between in Australia. After some searching, a student in Victoria found a site called Simply Scripts where film scripts can be downloaded for free. To find out more, go to <http://www.simplyscripts.com/movie.html>. (Source: Statewide Vision Resource Centre of Victoria)

Minimum qualifications for disability support workers

National Disability Services, (the Australian national disability industry agency) governance board has adopted a position on minimum qualification for disability support workers, which supports the development of a core induction program based on nationally recognised competencies. The issue of minimum qualifications has arisen in the context of the development of a national disability workforce strategy

UN Convention on the rights of persons with disabilities (CRPD)

Leading disability organisations in Australia have formed a project group to compile a Shadow Report on Australia's implementation of the CRPD. The aim is to make recommendations to the UN Committee on the Rights of Persons with Disabilities. These recommendations will provide the basis for the UN recommendations to the

Australian Government regarding Australia's implementation of the Articles of the CRPD. The main focus of the Shadow Report will be reporting the extent to which Australia has implemented its obligations under the CRPD and to provide recommendations for future action by the Australian Government.

Arnold Cielens

Arnold Cielens, disability advocate and champion, has died on 7 July, 2009, aged 87. This tireless advocate for deaf-blind people has fought his last campaign.

Arnold never stopped writing to politicians or advocating for people who fall between the cracks. He is one of the last of a group of early pioneers with disability who saw that it was their responsibility to advocate for those with weaker voices and was active in until his death in trying to secure better services.

The Editor writes: In my job, working for Sense as Education Officer in the 90's, Arnold was in touch with me very regularly about current policy. He asked me to send him our position papers and responses to government consultations which at the time were very important in lobbying our UK government for recognition and services for deafblind children.

His son Martin has set up a blogspot. Please visit!

<http://arnoldcielens.blogspot.com/>

Perkins International



The Michael T. Collins Young Leadership Award

In honor of his extraordinary contributions to the field of deafblind education around the world and in recognition of his desire to develop the field and ensure the future of his life-long passion, The Michael T. Collins Young Leadership Award will be bestowed every four years at the DBI World Conference and on alternative years at another International DBI Conference.

The deserving educator that demonstrates innovative practices and professional leadership will be

nominated by his/her peers and selected by a committee of Perkins International and Deafblind International leadership.

The recipient will be given a stipend of no less than \$1,000.00 to cover the costs associated with Conference attendance. These may include, but is not limited to Conference registration and/or travel and accommodation expenses.

The selected educator winner of The Michael T. Collins Young Leadership Award will be announced at the DBI Conference and recognized with a Framed Certificate.

UK

The National Practitioners Working Group on Communication was established in January 2007, inspired by similar networks set up across Europe, to focus on understanding communication development. The work of this group was recognised by Sense on 1st of October 2009 when Asun Snow and Mary Foster received the Sense Award on Innovative Practice on behalf of the group.

The group comprises of practitioners from different services within Sense. Many are in the role of shaping and developing practice. The National group meets regularly to share ideas and practice. Smaller teams, based on geographical areas, are facilitated by group members to cascade knowledge and understanding about recent developments in communication practice and to be the catalyst in setting up local projects.

We focus on meeting the challenges of working more successfully with people who are congenitally deafblind but our practice also affects others with a single sensory loss and additional disabilities and our overarching aim is:

To develop the way we support communication and interaction between congenitally deafblind children and adults and their communication 'partners'.*

*A communication 'partner' can be defined as any person who engages with a congenitally deafblind child or adult and attempts to communicate with them. For example, this could be a parent, brother or sister, Intervenor, carer or a teacher.

Within the national practitioners group, we are promoting the principles of how to be a good communication 'partner' to people who have complex communication support needs. We have drawn on practice based research and embraced the idea of supporting a natural conversational approach based on equality.

Key principles include:

- active listening by the partner
- giving TIME
- responding to an individual in a way that matches their own way of communicating
- sharing impressions, emotions, memories, thoughts and ideas in whatever way the person has available to them



Mary and Asun

- the partner supports this process of drawing out information from the person they are interacting with and trying to find out what their expressions might mean
- valuing different ways of communicating to enable us to learn from each other and introduce each other to our 'language'. In this way, we aim to reduce the frustration associated with not being understood.

It has been recognised for a long time that video is one of the most useful tools in helping us to understand our 'conversations' with people who are congenitally deafblind. We have developed and shared different ways of using video and video analysis, to help us understand what people are telling us and to identify the practical skills we need, as good communication partners, to support them. Some practitioners work with families and children to bring innovative practice at the most crucial times for the development of communication skills for children.

We are currently working on projects to:

- Create more opportunities for children and families to find out about current practice.
- Undertake research to collect examples of exemplary practice of enriching people's lives.
- Increase the use of video analysis across Sense, nationally, to develop the practical skills of those who support people who are congenitally deafblind and/or have complex communication support needs.

On behalf of the Group: Mary Foster, Asuncion Snow, Steven Rose, Graham Nolan



Award ceremony 2009: Bucharest June 25

The 17-strong jury assessed more than 1,000 applications from eight countries

The only award of its kind in the region, the ERSTE Foundation Award for Social Integration gives recognition to and promotes organisations and projects that aim to create a stable and just society including disadvantaged and marginalised groups. This year's call received more than 1,300 applications from eight countries in the region. Non-profit organisations, public administrative bodies, civil-society and private initiatives, religious communities and media organisations were eligible to apply. The projects work towards social change and creating a society with equal chances and opportunities for all. Only 20 projects were shortlisted.

Sense International Romania was the winner of 2 awards!

They were recognized for excellence in "Education for deafblind and multi-sensory impaired children" and also received a practitioner award.

The award ceremony provides the organisations with a platform that allows them to gain increased recognition of their often difficult work and with a forum for establishing contacts and networking with



potential partners and sponsors. The winners of the first ten prizes will receive special support in the form of a film about their projects. These films will be made available to the local and international media and may also be used for other purposes by the organizations.

"I believe we deserve this award and I appreciate all the other winning organisations for recognising the uniqueness of our project, working with a special category of beneficiaries – deafblind people. Until 10 years ago, it was thought that this special category of children could not be educated, but through an intensive programme we have managed to ensure that authorities integrate these children into Romanian schools. We have a special mission and we will continue to fight for supporting them.

Cristiana and the team with Dejan



International deafblind charity wins \$100,000 award

India

Sense International India, has won a \$100,000 award from the STARS Foundation. The award will assist the deafblind charity in its work throughout India. The charity was chosen for an Education Award because of its partnership approach. It set up South Asia's first teacher training and mentoring course in deafblindness.

The Ahmedabad based charity already reaches 27,000 deafblind people in India and works with 37 partners in 19 states. The award will mean it can continue its programmes with some of the most vulnerable children in India. Its goal is to reach 70,000 deafblind people by 2017.

Akhil Paul, Director of Sense International (India) said "For more than ten years Sense International (India) has been empowering deafblind people in India. To be one of just six organisations in the world to receive this award is a real honour and demonstrates our track record for transforming deafblind people's lives. We are deeply grateful to The STARS Foundation for the recognition but most of all it will help us to reach thousands more people and continue our campaigning



work in the region."

Muna Wehbe, Chief Executive of the STARS Foundation said: "Sense International (India) delivers truly unique services to children who without support would be isolated from mainstream society. Through its work with partners, the organisation responds to real needs, with tangible and effective programmes being provided to some of the most vulnerable children in the country."

For more information go to: <http://www.starsfoundation.org.uk/recipients-2/education-asia-2009/>

(Above, left to right) Mohamed H Jazeel, Akhil Paul and Biju Mathew

DB Ireland – 2nd National Training Event

Ireland

DB Ireland held its second national training event for professionals working in the field of deafblindness on Saturdays 21st November in Dublin.

Over 70 people braved atrocious weather to attend a free one-day course entitled "A matter of Communication – exploring a range of communication issues experienced by Deafblind children and adults"

The course focused on an overview of communication for deafblind people, functional vision and hearing assessments, challenging behaviour, video analysis and development of communication in deafblind children.

Experts in deafblindness from the UK and Republic of Ireland delivered the course and feedback from participants – which included a number of deaf and deafblind participants

was very positive.

The success of the past 2 events means that DB Ireland will be looking to make this event a regular annual feature of its activities.

Services in Republic of Ireland for deafblind people and their families and support for professionals all remain very inadequate. In the next year DB Ireland will be working to extend the range of its activities to address the numerous gaps in professional training, public awareness and support to deafblind people. Watch this space for details.

Ges Roulstone
Chairperson
Deafblind Ireland



Malta

More families in poverty – Maltese delegation in Brussels

Report from Maltastar.com

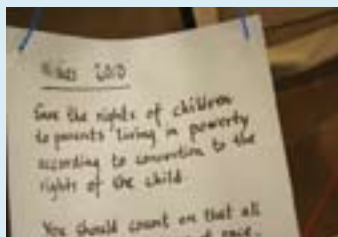
Utility tariffs are one of the issues raised by the Maltese delegation participating in the “Eight Meeting of People Experiencing Poverty”. This gives people experiencing poverty a chance to speak up and voice their concerns with national and European authorities.

Irene Schembri, Chairperson of European Anti-Poverty Network (EAPN) Malta said that it is very worrying that water and electricity bills remained high even after oil prices went down. She insisted this is pushing more and more families into the poverty trap.

Irene Schembri was also participating in the conference to speak on behalf of her son William, (we know him as Carl),

a deafblind youth.

“My son is one of the many Maltese disabled persons who have no voice, in some cases even literally, to express the bleakness in their future” she explained. In Malta, government provides accommodation services to just 38 disabled persons. Many parents have given up trying to apply for this service as it is so limited. Even worse, it offers no financial assistance to parents and relatives who have to give up paid employment to take care of disabled relatives. She explained that her husband has to keep up with three jobs to provide for all the expenses of the family, and for the additional costs required to provide for their disabled son”.



Moldova

Dear Sirs,

We are Association of Deafblind Children and Youth with Multiple Disabilities of Moldova “VITA”. More detailed information about us you can find on our site www.vita.md. This letter is, first of all, a message of greetings and the first step on the way of our acquaintance and, we hope, of our fruitful cooperation to enable better quality of life and education for deafblind and blind children with multiple disabilities.

Warmest regards,

Valentina Lebedeva, President

Hristo Botev str., MD 2043, Chisinau, Republic of Moldova

Cell phone: +373 69120015, Fax: +373 22 221535

e-mail: valentina@vita.md

Congenital deafblindness and communication

The magic of dialogue

Call for papers

February 1, 2010

Papers for free workshops are welcome. They must be about communication and congenital deafblindness, as much as possible in relation with the concept of dialogicality. They can contribute to the development of knowledge in this field by illustrating or questioning the dialogical paradigm and by suggesting or testing relevant methodological approaches.

The submission form is available for download at:

www.nordicwelfare.org/paris2010papers

DbI Communication Network Course

June 22 – 25, 2010

Paris • INS HEA 58/60 Avenue des Landes • 92150 • Suresnes



INS HEA



norden

Nordic Centre for Welfare and Social Issues

www.nordicwelfare.org/paris2010

Hope for deafblind children in Bangladesh

Biju Mathew reports on the work of Sense International India and the Centre for Disability in Development, Dhaka

Sadat is a 14 year old boy with total vision and hearing loss from Dhaka city. Having lost his father early in life, he is looked after by his mother and elder sister at home. With no services available for deafblind children in Dhaka, his mother had no option but to keep him at home. There was a ray of hope for Sadat and his family, when Rizwan, a special educator from Research and Educative Action on Disability (READ) began visiting his home to train him.

Today, after almost a year, Sadat has a special

relationship with his teacher. He identifies his teacher through touch and recognises his name sign. Rizwan has developed a training plan for Sadat with inputs from his mother and sister. He is being trained in his daily living skills, mobility, communication and undergoes physiotherapy. Sadat has mild learning disability as an associated condition which is hindering his learning process.

Deafblindness is not recognised in Bangladesh and there is no existing infrastructure to address deafblind peoples' needs and

rights. Neither the disability legislation nor a published disability prevalence study makes any reference to deafblindness. Due to this lack of awareness and expertise, deafblind people in Bangladesh have remained invisible with regards to public policy and specialist services, and excluded from the disability movement and society. This exclusion coupled with poverty makes deafblind children some of the most marginalized children in the country.

To address this issue, Sense International in partnership with Sense International

Sadat and Rizwan



(India) and Centre for Disability in Development, Dhaka (CDD), has initiated the project “Developing a sustainable infrastructure for the inclusion of deafblind people in Bangladesh” The aim of this project is to promote an inclusive society where deafblind people and their families have access to the advice, opportunities and support that is necessary to meet their unique needs and to enable them to access their rights.

In the long term we aim to establish a strong and supportive national infrastructure in order to increase services and provide a coherent voice for deafblind people in Bangladesh. Currently there is no provision for deafblind people and their families so this is a unique and vital project. The project is being delivered through local partners who are already working in the field of disability, in 6 districts of Bangladesh, to include Dhaka, Bogra, Munshiganj, Jessore, Gazipur and Narsingdi.

The lead partner CDD has established and managing a National Resource Centre to develop and disseminate information on deafblindness. Technical expertise is transferred from Sense International (India) to partners through a series of training and capacity building workshops and exchange visits. The project is modeled on our hugely successful work in India and sharing of expertise and experience developed over the last 12 years. The aim is to build capacity of

local organizations to be best practice models and encouraging local decision making to have control over their work.

Since the initiation of the work early this year, more than 80 deafblind children have been identified and are receiving services from the six partners. These children did not have access to any kind of support from any agency until they were identified under this project.

“The aim of this project is to promote an inclusive society where deafblind people and their families have access to the advice, opportunities and support”

Most of the parents did not have any information about their child’s condition and did not know where to take their children for support. Due to lack of awareness and information on deafblindness, even medical doctors could not give the correct diagnosis and guidance to parents. As a result, families had lost hope of any kind of support for their children who remained isolated. The impact of the work so far has been to kindle hope for these families. For community members, it has been a realisation that deafblind children can be

supported and educated. For organisations, it is a completely new challenge for them to take up deafblind work and be part of the first ever deafblind initiative in the whole country. Most of all, for deafblind children, a window to their world has been opened. It is the first time in years that someone has tried to communicate with them, understand their needs and made an effort to reach out to them.

The National Resource Centre (NRC) at Dhaka is providing the much needed support the partners by making available information on deafblindness in local language and co-ordinate training activities for the partners. It also produces the first ever newsletter on deafblind issues in Bangladesh. With support from Sense International (India) the NRC has organized the first national sensitisation workshop on deafblindness in Dhaka and has facilitated exposure and training visits for special educators to India. The Programme Support Unit at Sense International (India) provides on-site and off-site support to the NRC and partners regularly. The NRC is also initiating the first ever network of families of deafblind children in Bangladesh and is engaging with the government for recognition of deafblindness.

A new beginning has been made in Bangladesh, reaffirming our commitment to deafblind people. There are exciting and challenging times ahead and we welcome you to join us.

Biju Mathew



Touch You, Touch Me!

The First International Seminar / Workshop on Social-Haptic Communication

Helsinki,
Finland
6.-8.5.2010

Diaconia University of Applied Sciences (Diak) and the Service Foundation for the Deaf welcome you to the first international seminar on Social-Haptic Communication.

Touch You, Touch Me is an international 3-day seminar, which allows participants to learn and experience how to use social-haptic communication techniques and methods.

This seminar/workshop will introduce professionals and researchers who have been applying social-haptic communication in their own areas of research and practical applications for working with acquired deafblind people and now expanding to working with people with profound learning disabilities.

The seminar will be held in English and there will be a limited amount of places available with a maximum of 40 participants.

WHEN The 6th May – 8th May 2010

WHERE The seminar venue is situated in Diak's premises in Sturenkatu 2, Helsinki, Finland.

FOR WHOM The interdisciplinary seminar is aimed for sign language interpreters, teachers of the deafblind and blind, the deafblind, mobility and low vision instructors and different professionals working with deafblind and blind people.

PROGRAMME A detailed seminar programme will be released later. The three-day seminar / workshop includes e.g. the following themes:

- Haptics and Haptemes
- Haptics and perceptions
- Linguistic approach
- Practical every day activities (interpreting, IT, children, cultural activities)
- Deafblind persons' perspective using haptics

SPEAKERS **Riitta Lahtinen**, PhD, Researcher of Deafblindness, The Service Foundation for the Deaf: The seminar introduces the 15 years research produced by Riitta Lahtinen and her PhD thesis "Haptics and Haptemes – A Case Study of Developmental Process in Social-haptic Communication of Acquired Deafblind People" (2008).

Professor **Heikki Hämäläinen**, Cognitive Neuroscience, University of Turku

Russ Palmer, Music Therapist

A full list of speakers and workshop leaders will be released later.

PRICE 290 €. The price includes coffee on Thursday, and lunch on Friday and Saturday.

TRAVEL AND ACCOMMODATION The participants will organize and cover their own travelling and accommodation. Diak will reserve a number of rooms in a central hotel in Helsinki with a package price.

INTERPRETING The participants organize their own interpreting if needed.

REGISTRATION: Register online at www.turku.diak.fi/socialhaptic by the 1st February 2010.

FOR FURTHER INFORMATION, PLEASE CONTACT:

Diak: Niina Hytönen, manager of working life services, niina.hytonen@diak.fi, tel. + 358 40 866 7336

Service Foundation: Riitta Lahtinen, riitta.lahtinen@kuurojenpalvelusaatio.fi, tel. + 358 40 522 4201



SERVICE FOUNDATION
FOR THE DEAF

Education For All – VI update

Larry Campbell, President, International Council for Education of People with Visual Impairment



Dear Friends

It is a pleasure to have this opportunity to bring you up-to-date on developments related to the Global Campaign on Education for All Children with Visual Impairment (EFA-VI) launched by ICEVI in mid-2006 in partnership with the World Blind Union (WBU). As most of you will know from earlier updates, this initiative is directed at reaching the more than 4 million children in the developing world with visual impairment (including those with additional disabilities and children with deafblindness) who currently have no access to education.

The EFA-VI program is making strong efforts to work within the framework of the broader Education For All (EFA) initiative launched in 1990 by UNESCO, the World Bank and UNICEF. While the broad EFA program has made good progress in opening up primary education to millions of children in the developing world over the past two decades; the needs of children with disabilities have been consistently overlooked.

Despite this discouraging scenario we do see some real prospects for change on the horizon. Recently, Dr. Penny Hartin, WBU CEO and I met with the Acting Director of the Fast Track Initiative at the World Bank and were very encouraged by his interest in our work. He fully understands that the needs of children with disabilities have been largely overlooked and has expressed the desire of the World Bank to change this situation and work more closely with us in the months and years ahead. For your part, if you live and/or work in a developing country we urge you to

do all you can to encourage your government to include the needs of children with disabilities in their national plans for EFA. For further information on the EFA Fast Track Initiative you may wish to visit www.worldbank.org/education/efa. We also ask you to encourage your government to urge UNESCO to be sure that the issue of disability is on the agenda of the 9TH Meeting of the Higher Level Group on Education For All scheduled for late February, 2010 in Addis Ababa, Ethiopia.

Our target for Phase I of the EFA-VI program (2006-2010) is to reach at least 14 developing countries where active national task forces are in place, national plans developed and increasing numbers of children with visual impairment are attending school. While we have not quite met that objective as yet, we have reached 12 countries (see list below) and hope to have the program active and operating in at least two more countries before we convene our 13th World Conference and General Assembly in Jomtien, Thailand on August 9, 2010.

Africa: Ethiopia and Mozambique

East Asia: Vietnam and China

Latin America: Ecuador, Honduras, Nicaragua, Paraguay and the Dominican Republic

Pacific: Fiji

West Asia: Nepal and Pakistan

Expanding the reach of the program to include children with deafblindness has been quite challenging and this is why we look forward to the greater involvement of Dbi in the Global Campaign. The single exception to our failure to embrace children with

deafblindness as much as we had hoped can be seen in Latin America where there has been excellent collaboration between the EFA-VI program, national governments and our partners at CBM, ONCE/FOAL and the Hilton-Perkins Program. This has meant that the needs of children with deafblindness are being seen as an integral part of the national plans as they are developed. National Task Forces of the Campaign have been asked to strengthen collaboration with local organizations working for deafblind children in these countries and to prepare teachers with expertise in this area.

We hope that many of our colleagues from Dbi will join us at our 13th World Conference in August and we look forward to the participation of Dr. Bernadette Kappen 1st Vice President of Dbi at the EFA-VI Global Task Force and Executive Committee meetings of ICEVI in Bensheim, Germany in December.

Finally, may I ask that you share with us any important events connected with the services for children with deafblindness, so that we can post these on our website www.icevi.org in an effort to build stronger and broader awareness of the needs of deafblind children. Please send that information to ICEVI's Secretary General, Dr. M.N.G. Mani, sgicevi@vsnl.net.

As always,
Larry Campbell
President, ICEVI

A significant symbol...

Creating and sharing a beautiful art object

Ricard Lopez, from Apsocecat in Catalonia, discusses the way that art can change lives...

Guido Dettoni

My organization has recently started collaborating with Guido Dettoni, an artist with a wide professional background in the world of disabilities. Two wonderful projects have emerged from the exciting relationship between the artist and our organization. To start with, we have devised the creation of an experimental workshop targeted at deafblind people and their interveners: Moreover, Guido Dettoni has conveyed his own vision of deafblindness through his own artistic work and has created a piece of art he has



called Deafblind Shape.

The experimental creative workshop for deafblind people and their interveners has been created within the "handsmatter" framework, an artistic project created by Guido Dettoni which is based on experimenting with malleable materials. Our interveners and our congenital and acquired deafblind people have discovered a new way of communicating through plastic expression by sharing

in their hands a ductile material to create different forms and to set a unique dialogue "played by four hands".

Guido has also contributed his personal talent and has produced a beautiful sculpture called "deafblind shape". Created shortly after his introduction to deafblind people and linked to his close contact with interveners, this tactile form shaped at hands' size, conveys a positive outlook to the world

“With Guido’s work, I have been able to confirm how art can provide communication bridges where other codes do not work”



Merch and Enrica



Little hands...

of deafblindness with an unusual sensitivity and a great expressive power.

We both know how difficult it is to transmit the experience of any disability to the people who do not have a close contact with it. With Guido's work, I have been able to confirm how art can provide communication bridges where other codes do not work. The tactile form that Guido Dettoni offers, the "deafblind shape", manages to evoke our sensibilities. It is a tactile symbol of human and social nature; it is the witness of a reality. I believe this beautiful object could be a symbol of deafblindness all

over the world.

We have been sharing a common dream for many years and we have been working together towards the integration and the full development of deafblind peoples' potential. However, our horizon often fades away amidst the daily work and it is hardly noticed beyond those affected by any disability. In this sense I am convinced of the usefulness of a symbol where our values can be focused.

Associació Catalana Pro Persones Sordcegues
www.apsocecat.org



Experiencing the shape



Working the material

A lineographic, alphanumeric, data input system – that’s technical talk!

Alfredo Alvarado has a patent pending on an invention he hopes will support communication

Background of the System

Since ancient times there has been a universal need for communication among humans and other living creatures. This communication includes a variety of means such as human speech, sounds and body signs painting pictures or writing on cavern walls, using quipu cords to calculate, marking parchment or paper, imprinting clay tablets, reading and writing books, and currently sending messages via telegraph and telephone wires, receiving television, using computers, cell phones and different kinds of electronic gadgets.

People with serious sight problems can use their voice and hearing to communicate with each other, and in addition, if they have had language, they can use the braille method to read and write. However, deafblind persons need to communicate by other means such as touching to represent actions or situations, or by using a simple method such as printing with a finger on

the hand’s palm the letters of every word.

Deafblind persons can communicate using touch systems like the Malossi method in which different parts of the hand is touched or pinched representing different letters of the alphabet. This system, although useful, has significant limitations since it provides an alphabet with not too many capabilities for representing orthographic signs or mathematical symbols.

There is also a Malossi alphabet interface developed by Nicholas Caporusso of Alti Studi Lucca Institutions of Ponziano, Lucca that uses a glove equipped with sensors and actuators that enables communication using the Malossi language that is easily learned by the deafblind person.

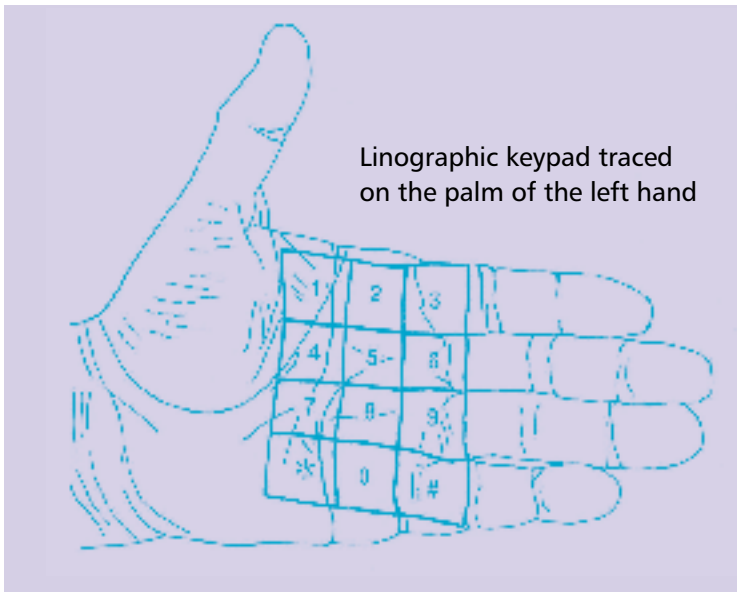
One alternative is the use of a hand-shaped keyboard that lets deaf and blind people send electronic messages that can be read on a computer display. This system was developed by engineers Ezio Manzoni and Alberto

Sannino in collaboration with students of Cesari Pesenti High School in Bergamo, Italy, and utilizes the Malossi alphabet described above that converts the pressing and pinching motions into electronic impulses that can be relayed to a monitor and read by a sighted person.

What is the Lineographic System?

The object of the lineographic system is to facilitate writing or text entry on a keypad integrated with a computer monitor, or a telephone screen. In addition, the lineographic system can be easily adapted for direct text entry on the palm of a deafblind person taking advantage of the skin sensors of the hand that will transmit the perceived signals directly to the brain. On the other hand the lineographic system can be modified for text data output for blind people using an improved braille that can be used in literary work, mathematics, science, computer software, and other variety of written materials. Another possibility is to translate the text entry into a machine that can print dashes and dots on a braille paper, similar to the braille system, but with the advantage of being more

“The object of the lineographic system is to facilitate writing or text entry on a keypad integrated with a computer monitor, or a telephone screen”



Lineographic keypad traced on the palm of the left hand

complete and allowing writing of more than 200 mathematical symbols.

The system is in 2 parts

The lineographic system has two components: One for the text entry or writing, and other one for text output or reading. Both have patents pending.

Text entry can be performed by using the data input system developed by Alfredo that eliminates the regular telephone keypad and the small buttons arranged in the conventional "QWERTY" configuration typically found on hand held devices. The system allows text to be entered into portable cellular phones, hand held computers and other electronic devices in a precise form by making linear traces or taps with a thumb or finger on a special pad. The system enables the user to enter operational commands on the pad as well as entering letters of different foreign alphabets. The alphanumeric pad has 12 touch sensitive cells that can be used for text entering of letters, numbers, punctuation

marks, orthographic signs and mathematical symbols.

The text output or reading component is designed to convert the input traces made on the alphanumeric pad into an improved Braille that provides a universal code that can be used with different materials such as literary text including various foreign languages, mathematics, science and computer software. The main advantage of the system is that it can use a large number of combinations due to the fact that it employs a 12-dot code. The numerals can be represented in their simplest form without the need of indicators, as in the Braille system, and this would help enormously to facilitate execution of mathematical operations. The input traces of the lineographic system can be translated into raised dashes and dots on a special braille paper than can be perceived with the fingers by a blind person. The raised dash indicates the initiation of each character and the following raised dots (similar to the dots

used in braille) will complete the representation of the character. Each character is contained in a particular embossed frame, but it can be modified by omitting the embossed frames which is particularly destined to experienced braille readers. Another alternative would be to use a braille board provided with movable dashes and dots that are activated by a microprocessor and chip controller.

A non technical option

Recently, Alfredo developed a third lineographic system based on the same system that would facilitate communication among visually impaired people, particularly deafblind persons who have the more severe form of disability. The new system does not require the use of any machine or computer and is ready to be used anywhere. This system is a tactile method on the hand and the lineographic method is replicated by making short linear traces in the appropriate place on the hand. The method is the same as many tactile methods already use by deafblind people to communicate language but the advantages of the lineographic method would be that it would extend the amount and quality of alphanumeric information that could be processed because it does not use ordinary language but the code system.

Alfredo's complete article is at www.deafblindinternational.org

8th

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ADBC

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www.deafblind.org.au



www.ableaustralia.org.au

Our hosts – the Lega del Filo d’Oro



The theatre



Elizabeth Hodges and Gail Duece



*Workshop in
Chiesa dei Concelli*



*Bernadette with
Rosanno Bartoli,
a wonderful
host, with his
DbI Award for
Distinguished
Service*



*Welcome to
Senigallia*



La Rocca



Rotonda a mare



The sea front

Ton Visser Dbi Distinguished Service Award

A modest, hard-working professional who changed the lives of children who are deafblind nationally and internationally Ton has, over his 40 year career, worked tirelessly to improve the quality of education for the children. As a teacher he worked with a population of children with congenital rubella. This was a new group of children who little was known about and each day was a learning adventure for the teacher as well as the student. From the very beginning of his work he was interested in the communication development of the children. He saw the need to give the students a way to express themselves and gain knowledge about the world around them.

He was appointed to the position of the director of Rafael School and in this capacity he used his leadership skills to develop the school into an internationally recognized educational program. Under his



leadership he focused on teamwork and encouraged a coaching model with the staff and provided high quality in-service training so that all staff felt competent in their roles. As the school grew so did the need for a larger facility. He had to work with the staff, architects and builders to create a new school. He travelled to other programs to get ideas for the new school building. Again he was always looking to the future to be sure that he students received the very best education.

As a result of his hard work and interest in staff development, he finishes his career as the Director of the Center of Expertise. He worked cooperatively with the University of Groningen to set up the position of Chair of Congenital and Early Acquired Deafblindness.

Throughout his career he has been involved with Deafblind International. He has been a presenter at many conferences and has been a member of two Scientific Planning Committees. Since 1992 he has been a member of the Dbi Communication Network

He has been a member of the Dbi Management Committee and has served in the role of treasurer. Under his leadership Dbi has improved its financial picture and is moving toward formal association status. At every Dbi Management Committee meeting his wisdom and clear thinking benefit the organization.

Bernadette Kappan

Inger Rødbroe

Dbi Lifetime Achievement Award and Ann Sullivan Award

Inger is a visionary who started her career as a teacher at the school for the deaf and later served in a variety of administrative/leadership roles at the school and throughout the country.

In a letter of support the writer says "She always placed the deafblind person in the center, and she always recognized the particular expertise of the parents... she is a part of our history."

Her work has been deeply rooted in encounters with people. An encounter with a deafblind person fills her for the moment and from that moment springs deep concern about how she can herself contribute to the improvement of the situation for that particular person.

This approach has characterized

her entire career.

She has worked in her own country, in the Nordic countries, and throughout Europe. Her knowledge in the area of communication and her teaching skills brought international invitations to lecture and train parents and professionals. Her international connections are many but she has focused her efforts in Africa and Nepal.

Her leadership had influenced policy makers and resulted in the revision of the Nordic definition on deafblindness and recommendations for services to deafblind individuals and the need for quality staff training. As a member of the Communication Network she has worked tirelessly to bring the work to publication.



One letter of support speaks to her persistence until the mission has been completed – this can be seen in every task she has taken on throughout her career. She has travelled the world, lectured, informed, given guidance and support and raised awareness of deafblindness with kindness and determination.

Bernadette Kappan

Peter Fasung: Slovakia

In the early 1980's Peter and Ivana Fasung became parents to Kristina, their deafblind baby. At that time in Slovakia there were no services or education programs for deafblind children, however around 1990 a small education program for deafblind children started in the village of Cervenica in eastern Slovakia. This was accomplished through the efforts of the state and the Evangelical Diacony Church. Kristina was one of the first children to attend and over time it grew to 12 students.

“Peter is a person who shares his families’ experiences and his own determination with others.”

In 1998 the Association of Parents and Friends of Deafblind Children in Slovakia was established to help advocate for the unique needs of their children. As the parents watched their children learn, mature and become more independent, they became concerned about what would happen when their children's education was finished. Peter Fasung, as one of the founding members of the Slovak Parents' Association,

has spearheaded the Slovak national effort to establish the first group home for approximately 6 – 10 people. Through much planning, fundraising and blood, sweat and tears, the Association has purchased a house and reconstructed it to meet government requirements. This was a labor of love that consumed many, many years. Proudly 'Maják' opened as the first group home for deafblind young adults in March of 2007.

Peter is a father who also shares his passion for advocacy with the Czech Parent Association so they may achieve similar services within the Czech Republic. More than an advocate, Peter is a person who shares his families' experiences and his own determination with others. Many of us who have attended the 'Listen 2 Me' family gatherings or other European meetings have been touched by his openness and insight. In doing so, he inspires all of us to find both perspective and strength.

Sergei Sorokin



Patrizia Ceccarani: Italy

“I got to know about the Lega long ago in August 1969 and I 'fell in love' with it so much, I decided to become a volunteer”.

At that time the Lega del Filo d'Oro was a small Association which supported deafblind adults, encouraging awareness and

integration. Deafblind and multisensory impaired children were looked after by a Rehabilitation Centre. Patrizia learned about the world of deafblindness as a volunteer, particularly about multisensory impaired children. Her interest intensified. And she wanted to work concenterly to meet their needs.

She enrolled at the University of Bologna in 1970 and in 1974 got her degree in Special Pedagogy. She wrote her thesis on secondary autism, communication and education for deafblind people. In addition, she

decided to go to an international course in Holland on the education of deafblind children. She made contacts with other professionals which have endured right up to now.

In 1974 Patrizia joined the Lega del Filo d'Oro as a pedagogist. Her belief in research and training to find effective solutions for the deafblind. She understands that contacts made with foreign professionals are fundamental for keeping up-to-date and for increasing scientific knowledge.

Despite her numerous commitments, she is still a teacher on specialisation courses for teachers and assistants. She has published some books and collaborated on editing specialised journals on handicaps, such as HD. Patrizia's interest in medicine and collaboration with medical specialists led to the founding of the Diagnostic Centre in 1990.

Patrizia took on the management of rehabilitation at the Osimo centre, first as a temporary measure (1994) and then permanently and she also supervises the "new-born" Lesmo and Molfetta services and the Day Centre in Pescara.

Sergei Serokin

Deafblind expert David Brown receives honorary degree from CMU

David Michael Brown received an honorary Doctor of Science degree from Central Michigan University in May. Brown, an education specialist with California Deaf-Blind Services, has given various lectures and training programs around the world. His published work has been translated into several languages. He serves on several advisory boards including the CHARGE Syndrome Foundation and been awarded many professional honours for his volunteer work.

David Brown, from Wales originally, established Sense's (UK) family led assessment and support service for deafblind children and is widely revered and fondly regarded by families all over the world.



Photo By Robert Barclay,
CMU University Communications

David Brown receives an honorary Doctor of Science degree from former Central Michigan University President Michael Rao.

Dr Mike Steer AM – for Service to Education

Dr Mike Steer, a tireless worker within RIDBC Renwick Centre and in the international field, was appointed a Member of the Order of Australia in the recent 2009 Queen's Birthday Honours.

As RIDBC's Senior Lecturer in Vision Impairment, Dr Steer, with Lecturer Fran Gentle and the assistance of some of RIDBC's specialist staff, guides professionals through Graduate Certificate, Masters Degree and PhD level courses, equipping them with the necessary skills to teach and assist people with vision impairments. He has developed this service with exceptional success.

Sharon Barrey Grassick writes:

In addition to his contributions to the field of Vision Impairment, Mike has also made enormous contributions to the field of deafblindness, including the following:

- an active member of the ADBC (Australian DeafBlind Council) since 1997
- editor of ADBC's newsletter, Beacon.
- instrumental in organising courses at Renwick Centre specific to Deafblindness and Multiple Sensory Impairment, bringing a number of international speakers to Australia
- a mentor to many students and staff members.

"Personally, I have found Mike's knowledge and wisdom invaluable in regard to support and services to people who are deafblind in Australia. He is one of a kind and so very deserving of this honour – one of Australia's most prestigious".

The grateful Editor of this magazine comments:

"Mike has proved to be a tremendous "Country Correspondent" for Dbl Review! His comprehensive copy is a pleasure to receive – always full of activities and public policy developments reflecting this vast region. As we converse by email Mike never forgets he is "a son of Devon" (a beautiful county in England) and also keeps me updated with sporting and climatic developments down under! Thank you Mike and warmest congratulations and well deserved!"



Mike and his wife Maggie

Mike's citation reads:

"For service to education through the Royal Institute for Deaf and Blind Children, and to the promotion of professional standards for vision support teachers in Pacific Island countries"

Communication and Congenital Deafblindness

After five years four booklets and DVDs are the result of a Dutch – Nordic project on Communication and Congenital Deafblindness. The four booklets are written in English, but separate translation packages have been developed for translation purposes into other languages by organisations in the field of deafblindness. The translations into Danish, Dutch, French, German, Swedish, and Finnish are ready or are running. Translations into Polish, Russian, Spanish, and Portuguese are planned to start in the near future. Perkins School for the Blind in Boston are reprinting the English booklets for the overseas market.

The main purpose of the project is to make the current knowledge on how best to develop communication with congenital deafblind persons available for families and professionals involved in the field. The project emerged within Deafblind International's Communication Network and is therefore closely related to the theoretical framework being developed within and around this network since the late 80ties.

The main content of the booklets follow the following format:

1. general knowledge on how all human beings develop
2. deafblind specific knowledge and practical

- intervention strategies
3. written examples and video illustrations on how to imply this knowledge on an individual level.

The booklets should address all ages and give examples of the big differences in the present population.

The feedback we have got till now, is that the knowledge is practise based and well structured in a theoretical framework and visualised with good practise examples on the DVD. Just what professionals in the field need in their practical work and for staff development programmes.

The titles of the booklets are:

- I Congenital deafblindness and the core principles of congenital deafblindness
- II Contact and social interaction
- III Meaning Making

- IV Transition to the cultural language.

Without the hard work and the willingness to share knowledge from many Nordic and Dutch professionals and the financial support by Revalidatiefonds (The Netherlands), Det Obelske familiefond, Oticon Fonden, Det Kommunale Momsfond, Nordic Centre for Welfare (Denmark), this would not have been possible. The project leadership concerning the content was in the hands of Inger Rødbroe (The Danish Resource Centre on Congenital Deafblindness). The technical project leadership was in the hands of Annet Eikelboom (Viataal). **The booklets in English and Dutch can be ordered via viataalshop@viataal.nl; in Danish via www.matcen.dk; in Swedish via www.nkcdb.se; and in French via www.cresam.org**



News from World Federation of DeafBlind people

Lex Grandia reports



A range of events with 42 countries represented...

Speke Resort, Munyonyo, on the shore of lake Victoria in Uganda was the wonderful setting of a range of events organised by WFDB October 21-27 2009. 250 international participants and 150 from the host country Uganda participated. Deafblind delegates from 42 countries worldwide with interpreters and representatives from many of WFDB's partner organisations came together for the Founding General Assembly of the new continental organisation African Federation of the Deafblind, the annual meeting of the Latin American Federation of the Deafblind, Flasc, the 9th Helen Keller World

Conference and the 3rd General Assembly of the World Federation of the Deafblind.

AFDB

In 2004 WFDB initiated the process of establishing an African Federation of the DeafBlind. WFDB together with partner organisations like FSDB and SHIA from Sweden, Perkins International, CBM, AFUB (the African Union of the Blind), Sense International and the Secretariat of the African Decade of Persons with Disabilities have organised training courses and meetings of African representatives of deafblind organisations and national groups on their way to establish national organisations of persons with deafblindness.

On October 21st and 22nd, 2009 the Founding General Assembly of AFDB took place. The constitution was discussed and adopted and deafblind representatives of 12 African countries elected an Executive Board. The Executive Board should have five members, representing five African regions, but North Africa has no representative yet in AFDB, so the Executive Board has the following members:

President: Ezekiel Kumwenda, Malawi, South
Vice-President: Sansan Daj, Ivory Coast, West
Secretary General: Agnes Abukito, Uganda, East
and Board member: Edouard Massamba, Congo Brazzaville, Central.

The AFDB General Assembly adopted a resolution, which reads as follows:

1. The newly elected Executive Board shall, with immediate effect, implement a programme to build the capacity of its members by establishing national deafblind organisations in countries where they do not exist, and strengthen the existing ones.
2. The newly elected executive board shall with immediate effect establish a secretariat of AFDB to implement Deafblind programmes/projects

3. Three newly elected executive board shall with immediate effect form a financial and fundraising committee which will be responsible for mobilizing resources for AFDB programmes/projects.
4. AFDB shall assist member countries whose government has not yet ratified the UN convention on the rights of persons with disabilities to advocate for the ratification.
5. AFDB shall ensure that deafblind girls and women are given equal opportunities in all AFDB affairs
6. AFDB expresses its gratitude to the interim committee of AFDB and WFDB for the efforts made during its establishment."

Flasc and EDBU

Eleven deafblind representatives from the Latin American Federation of the DeafBlind, FLASC, held a meeting on October 22nd. The board of the European DeafBlind Union, EDBU had a meeting on October 25.



The 9th Helen Keller World Conference

The theme of the HKWC on October 23 to 25 was " The Convention on the Rights of Persons with Disabilities... changing the lives of persons with deafblindness".

Plenary sessions discussed themes like: what is an international legal document, how does the UN system work; how can organisations of persons with deafblindness be involved in the implementation of the CRPD and the process to ratification; what happens when a country has ratified; the importance of

establishing alliances with other disability organisations in the process of implementation of the CRPD and what should be changed in national legislation to address the rights of persons with deafblindness.

Workshops had different themes from CRPD like: employment, communication, information technology, legal capacity, Women with deafblindness, education, HIV/AIDS, interpretation, recognition of deafblindness and the importance of partnerships, the use of weapons that cause deafblindness.

Abdel Diallo and Yaya Sidibe Mali translate from English to French and write on notepaper for deafblind delegate from Mali, Noukany Bagyako, who reads using her magnifying glass



A school visit

The newly elected Executive Committee of the new African Federation of the Deafblind, AFDB; from left:

Edouard Massamba, Congo Brazzaville, Central Africa;
 Agnes Abukito, National Association of Deafblind Uganda (NADBU) East Africa, Secretary General of AFDB;
 Ezekiel Kumwenda, Malawi, Southern Africa, President AFDB;
 Sansan Dah, Ivory Coast, West Africa, Vice-President AFDB



During the Friday evening October 23, WFDB celebrated the 200 years anniversary of Louis Braille. Many participants brought examples with them to show the use of Braille in every day life.

The Saturday evening the Silent (deaf) Theatre from Uganda performed a realistic play in sign language and the Sunday afternoon was spent on a visit to the Ntinada School for the Deaf in Kampala.

WFDB 3rd General Assembly

On October 26th and 27th the WFDB 3rd General Assembly took place. Many reports were discussed and a new Executive Council and other committee members were elected as follows:

- President:** Lex Grandia, Denmark
- Vice-president:** Sonia Margarita Vilacres, Ecuador
- Secretary General:** Geir Jensen, Norway
- Treasurer:** Christer Nilsson, Sweden
- Regional representatives:**
 - Africa:** Ezekiel Kumwenda, Malawi
 - Asia:** Satoshi Fukushima, Japan
 - Europe:** Sanja Tarczay, Croatia
 - Latin America:** Alejandra Caranza, Argentina
 - North America:** Jeffrey Bohrman, USA
 - Pacific:** Irene McMinn, Australia
- Auditors:** Agnes Abukito, Uganda
 Dimitar Parapanov, Bulgaria
- Election committee:** Riku Virtanen, Finland
 David Shaba, Tanzania
 Miriam Torres, Venezuela

The General Assembly decided to form more thematic working groups in WFDB involving as many persons with deafblindness as possible. It was also decided, that WFDB should work on the promotion of a UN international day of deafblindness on June 27.

The WFDB General Assembly adopted a resolution with the following text:

Resolution of the Helen Keller World Conference and the 3rd General Assembly of the World Federation of the Deafblind Munyonyo, Uganda

We, the members of WFDB gathered in Munyonyo, Uganda, representing all people living with deafblindness, considering the historical moment in which the 3rd General Assembly of our organization takes place; taking into account the challenge that the implementation of the Convention on the Rights of persons with Disabilities represents, we share the following resolution:

1. WFDB is committed to the necessity that every country in the world ratifies and implements the Convention on the Rights of Persons with Disabilities.
2. Persons with deafblindness and their organizations have to take the lead in the process of implementation of the Convention on the Rights of Persons with Disabilities in all parts of the world.
3. We identify education as a primary issue, being essential to enable inclusion of persons with deafblindness in all aspects of life.

At school





Satoshi Fukisima from the Japanese Deafblind Association, the host of the 10th Helen Keller World Conference in Japan 2013. Satoshi's interpreter is writing finger braille on his fingers

4. In developing countries special attention should be given to the specific needs of persons with deafblindness in education, including provision of technical aids, proper materials and adequate numbers of qualified teachers and guide/ interpreters.
5. WFDB should facilitate that the Convention is accessible to all persons with deafblindness using all formats of communication.
6. To achieve a better impact at a national level, the Convention on the Rights of Persons with Disabilities should be translated into national languages and specific guidelines should be developed in plain language.
7. Governments should address rubella as an important public health matter that is one of the main causes of deafblindness.
8. Policies aiming for inclusion of persons with deafblindness in work and productive activities have to be promoted at international organizations like the ILO.
9. The WFDB should facilitate the formation of women groups and promote the inclusion of women in different areas as education and health care, promote the legal capacity and access to information of women with deafblindness.
10. Research and data collection that can favour the life conditions of persons with deafblindness must be supported.

The next 10th Helen Keller Conference and 4th WFDB GA will take place in Japan, in May 2013

Meeting of development partners

WFDB organised a meeting of partners in the deafblind field working in developing countries. DBI, CBM, Perkins International, FDDDB, DPOD Disabled persons organisation Denmark, FSDB, SHIA; ABILIS, Sense International and AFUB participated in the meeting and presented their organisation and work.

All agreed that it is important to share information about the work in developing countries.

Lex Grandia

Patricia Nakagulire and Agnes Abukito, President National Association of Deafblind Uganda (NABDU)



The 12th European Deafblind Week

**European Rehabilitation and Cultural Week
of The Deafblind 2010**

in Tübingen, Germany

(formerly known as the European Deafblind Holidays)

Monday 2nd to Sunday 8th August 2010

Hosted by "the Association of the Deafblind in Baden-Württemberg (Germany)"
and the "diocese of Rottenburg-Stuttgart – pastoral care for deafblind people"

Dear Friends,

We are able to confirm that the 12th European Deafblind Holiday will be arranged in Germany!

Welcome!

This is a warm invitation to all deafblind people who live in Europe, to participate
at the 12th European Rehabilitation and Cultural week of the Deafblind.

This week will be arranged in Tübingen, near Stuttgart in the south of Germany.

Where?

"Tübingen is an enticing and dynamic Swabian city of culture! It's 5 miles southwest of
Stuttgart Airport/Trade Fair, with about 90,000 inhabitants and 23,000 students.
Since its founding in 1477, the university has shaped the character, formed the appearance
and brought life to the Universitaetsstadt Tübingen. The university hospitals not only
employ many people but also attract patients and visitors from far and near."

www.tuepps.de/tuebingen-english.htm

Participation

The participation fee amounts to 450 Euros per person.

It includes accommodation, full board and activities.

It is possible to apply for financial support to participate at the European Deafblind Holiday.

The maximum amount of money individual participations can apply for is 100 Euro.

More information concerning the programme for this week, registration,
accommodation and transport will be given in October 2009

Please contact

Katholische Seelsorge für Menschen mit Hörsehbehinderung/Taubblindheit

Diakon Peter Hepp

Im St. Michael 39, 78628 Rottweil, Germany

Tel.: 0049-741-2902642, Fax: 0049-741-2902641,

email: Peter.Hepp@drs.de

News from the Secretary and Secretariat

Since Senses Foundation took over the Secretariat position in 2008 we have been busy following up actions and implementing new systems to streamline the work we do for Dbl. Outlined below are the main focus areas of our work since we last reported to you in the July 2009 Dbl Review.

Conferences and Meetings

The Secretariat was pleased to support the hosts of the Dbl 7th European Conference 2009 by circulating announcements, encouraging participation and promoting the conference programme to the worldwide community. Dbl members, past and present as well as the delegates who attended the Dbl 14th World Conference in Perth were contacted regularly to keep them informed of the conference activities and planning progress.

It was a pleasure and a privilege to attend the Conference in Senigallia. We were proud to host the Dbl booth at the conference and enjoyed the opportunity to meet some of our members in person and welcome new members face to face. Aside from the world class conference program and social events, it was a delight to enjoy and experience the wonder of Senigallia. With its beautiful cobble stoned streets and walled city with Roman statues; fountains and piazzas everywhere, it was



Elvira Edwards and Bronte Pyett

quite a change of scene from our Australian landscape and culture.

Prior to the conference, the Management Committee and Council held meetings to report on progress achieved and to make some significant decisions for Dbl. The key topics of discussion at the Council meeting were the new Dbl constitution; the new Dbl Strategic Plan; forthcoming conferences including the 15th World Conference in 2011 and the next European conference in 2013 along with a number of smaller ones in other parts of the world; and receiving reports from Dbl's many committees throughout the world. At the Extraordinary General Assembly, the new Constitution was ratified.

Earlier in the year, the hosts in India sadly had to withdraw from organization of the Dbl World Conference in 2011. There were several reasons for this: growing concern for civilian safety in India and the financial strain caused by the global economic crisis. Following this news, a call for Expressions of Interest was sent to Dbl's extensive database inviting organizations to submit

an application to become the new host. From the applications received, Council ratified Brazil as the new host and we are delighted to be working with them in the lead up to what is sure to be a spectacular event. As preparations unfold we will share the developments with members through regular email communication. Council also ratified France as the next host of the 2013 Dbl European Conference. Congratulations to both host countries.

Following the meetings in Senigallia we will be working hard to complete the actions from the Matters Arising. Already some of these actions have been progressed successfully and documents have been updated to reflect the extensive work that has been done by everyone.

We would like to take this opportunity to thank Dbl President William Green for his unwavering support in the lead up to the ManCom & Council meetings. His assistance in making arrangements for travel, transfers and accommodation requirements made the journey to Senigallia a smooth and pleasant experience.

The Management Committee will next meet in Sao Paulo, Brazil in February 2010. Preparations for this meeting are already underway and a meeting with the local planning committee for the 15th World Conference will take place there to assist the local

hosts with their conference planning processes. ManCom will take this opportunity to tour the proposed conference venue and facilities.

Membership

Thank you to all members who renewed their membership this year and we extend a warm welcome to our new members. Earlier in the year, a Dbl pin was designed and produced. We will be pleased to send members a pin at the time of each membership renewal. Early in 2010, members whose membership has expired will receive an invitation to renew. We hope you are in a position to continue your partnership with Dbl and encourage members to keep in regular contact

with the Secretariat so we can continue to grow and improve Dbl's membership. Please remember to alert us of any changes to your contact details, including email addresses.

If you would like an update on the status of your membership please contact the Secretariat on secretariat@deafblindinternational.org.

Website

The website continues to be an excellent source of information and we aim to keep the information up to date and interesting in liaison with the Information Officer. We are excited to be moving into a new phase in 2010 which will transform the way we operate. By moving towards more of an

E-function we will evolve and aspire to be a great website. We encourage all members to provide regular updates on the work you are involved with so we can keep the website accurate and help spread the word about the important work and progress we are making in the field of deafblindness.

Thank you

Thank you to you all for the ongoing support this year. We await 2010 with a bright outlook and a real desire to make positive improvements for Dbl in our role as Secretariat.

Elvira Edwards,
Bronte Pyett
Secretary Dbl
Secretariat Manager Dbl



Dbl is a vital network for all involved in the field of deafblindness. In order to best serve our members, it is crucial that we raise sufficient funds through fees to finance our basic activities. With this in mind, there is a Corporate as well as an Individual membership form for you to fill in. Please encourage as many people as possible to join.

Non-Voting Members consist of individuals, national networks and non-subscribing Corporates. Non-voting members can contribute to the decision making process of Dbl through either a corporate member or an international network. Non-voting members will receive a copy of Dbl Review and other relevant Dbl information.

Non-voting membership costs €30 a year or

a discounted €100 for four years.

Voting Members are the representatives of corporate members who have paid their subscription fees, and the representatives of recognised Dbl networks.

There are now three tiers of **Corporate Membership**:

Large Corporates:

Annual Fees between €3,000 and €5,000

Small Corporates:

Annual Fees between €300 and €1,500

Mini Corporates

Annual Fees between €100 and €250

Library membership fees €50 annually

Corporate Members can be nominated to sit on the Council.



Deafblind International Individual Membership

- I would like to join DbI as an individual member
- I would like to renew my DbI individual membership

Member details Membership No. _____

Title Surname First name _____

Organisation _____

Job Title _____

Address (Line 1) _____

Address (Line 2) _____

Town/City State/County _____

Zip/Post Code Country _____

Telephone no. Fax no. _____

(Please include country and area codes)

E-mail address: _____

Are you:

- a deafblind person a family member a professional

Does your organisation work primarily for/with:

- blind people deaf people deafblind people
- disabled people other (please specify)

Your contact details will be made available to DbI members for DbI purposes but will not be made available for commercial purposes.

DbI Review (please check one box in each category)

I would prefer to receive *DbI Review* on: paper disk*

(The disk version of *DbI Review* is supplied in text only format, on floppy disk)

Membership Fee please tick where appropriate

- I wish to pay for 4 years' membership at the **discounted rate of €100**

Corporate Membership

There are three tiers of Corporate Membership:

Large corporates Annual fees between €3,000 and €5,000

Small corporates Annual fees between €300 and €1,500

Mini corporates Annual fees between €100 and €250

Mini Corporate membership is available to interested organizations from the World Bank list of Heavily Indebted Poor Countries and Low Income Countries

- We would like to join DbI as a Large / Small / Mini Corporate Member

- Library membership fees €50 annually

(please delete as appropriate)

We submit an annual fee of € _____

Corporate members are entitled to receive 25/10/5 copies respectively of *DbI Review*.

We would like _____ copies

Member Details:

Organisation _____

Representative _____

Address (Line 1) _____

Address (Line 2) _____

Town/City State/County _____

Zip/Post Code Country _____

Tel: Fax _____

(please include country & area codes)

Email: _____

Website: _____

How to pay?

In order to enable us to put your entire membership fee to use, we would kindly ask you to avoid sending us cheques as far as possible. By arranging your fee via bank transfer, we are able to keep banking charges to a minimum, thereby increasing the value of your membership fee. Naturally, for those of you who do not have access to this facility, we will be delighted to accept your fee by credit card, cheque or in cash.

Payment method Bank Transfer Credit Card Cheque

A) Payment by Bank Transfer

If paying by bank transfer, please make payment to the following account:

Name of Bank: RABOBANK
 Address of Bank: Sint-Michielsgestel, The Netherlands
 Account Name: Instituut voor Doven: INZAKE DBI
 Account Number: 11.29.09.825
 Swift Address: RABONL2U
 IBAN: NL31 RABO 0112 9098 25

Date of Bank Transfer: _____

Please quote the Swift Address and IBAN number in your instructions for Bank Transfer (If this is impossible and you have to send a cheque or international postal order then please contact us)

B) Payment by Credit Card

Card type: VISA American Express Mastercard

Card no:

Expiry date Name on card: _____

C) Payment by cheque

Please make cheques payable to "Stichting Viataal Zorg inzake DbI" and post to: Ton Groot Zwaafink – DbI Treasurer, Theerestraat 42, 5271 GD, Sint-Michielsgestel, The Netherlands. If paying by Eurocheque, please make out cheque in euros.

Please fax this whole page to (08) 9473 5499

or return to:

The Secretariat, Deafblind International, PO Box 143, Burswood WA 6100, Australia

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