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Review



Bangladesh

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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.

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Cover: DbI Asia Conference, Bangladesh

A message from the president

Dear members, friends and colleagues!

I said in my last message that DbI will be looking closely at our future strategy over the next year leading up to our planned conference in Perth 2007. I am happy to inform you that a strategic planning group has now been formed, led by Tony Best, and has already had its first meeting hosted by Overbrook School for the Blind. I am looking forward to the outcome and the recommendations from this group, as I am sure they will have great significance for the future of our organisation.

Thinking about this group and its members I started to consider how many people are actively involved, either directly and indirectly, in thinking about the future of Deafblind International. If I take into consideration our network committee, nominations committee, conference evaluation group, our recognised network activities, our conference hosts as well as the everyday work of the management committee and the secretariat – then the number is quite astounding! So many people are doing things for the future of deafblind people and the people significant in their lives we can only say a special thanks to those who give so much time and energy to our common goals.

Previously, I mentioned the



preparation of a document entitled a “memorandum of understanding” with ICEVI. I am pleased to announce that this has now been completed and duly signed by the President of ICEVI, Larry Campbell, and me. I look forward to a close collaboration with this organisation and we have already planned to have our next Council meeting alongside their World conference in Malaysia in July this year. Another natural partner is the World Federation of the Deafblind, with their president, Lex Grandia, whom many of you know. Lex will be attending our Council meeting in order to maintain our positive future working together.

In this Review you will read an in-depth report from Bangladesh. I have to say what a fantastic experience I thought the conference was. The participants from many countries really impressed me with their passion, feelings and thoughts. The conference

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was well organised and the programme and speakers really stimulating. I know a lot of hard work went into this and would like to congratulate all those involved for this successful event. I hope that the same energy will contribute to the development of services in this part of the world. I am sure it will!

Once again another highlight this year was to attend the conference on Communication in Oslo. Organised by the Nordic Staff Training Centre with a programme involving and developed by members of our Communication Network working group. Over 100 participants discussed areas related to communication. I know these ideas will be made more widely accessible in due course as this theme has so much interest all around the world. I am also looking forward to, and hoping for, a closer collaboration with NUD in the future.

Looking at the agenda of

events planned for autumn this year I am pleased to see some of our networks so active. EdbN are holding a family event in Salou in Spain and ADbN is having another conference in its very successful series – this time in the Netherlands. Look for the details – they are here in the magazine.

Next year, of course, is the Dbl World conference to be held in Perth, Australia. The planning is underway for what promises to be a wonderful event in a fantastic setting. The call for papers will soon be out and I hope you will all be willing to share your ideas and activities with us all.

As usual I will finish by welcoming the new organisations that have joined us recently. My sincere thanks to all of you who are continuing their support to Dbl and in consequence to deafblind children and adults and the people who are significant in their lives.

William

EDITORIAL

You can take a trip around the world with this edition of the Review – and in the company of tremendous people!

The Asia Conference gave us the chance to meet new colleagues in Bangladesh and the survey we fortunate to be reporting provides both an explosive piece of evidence to support the start of formal work with deafblind people. The film that accompanies the report is both moving and powerful – a great tool for campaigning.

Through Klaus Vilhelmsen

we have another in our series of articles about the value of aesthetic experience and this time our authors report on a music project.

Things are very lively in Central and Latin America – from breadmaking in Brazil, to bowling in Colombia, to a family event in Guatemala! India features, as does Africa – and there is news aplenty from Australia!

Keep in touch – it's your ideas we need!

Good wishes

Eileen

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An invisible, silent world

The situation of deafblind people in Bangladesh

The Dbl Asia conference in January this year was an outstanding success. At its heart was a report commissioned by the Host organisation, NFOWD, and undertaken by its General Secretary, A.H.M. Noman Khan with study consultant, Sadaf Noori Chowdhury. Along with the report, entitled "An Invisible Silent World", a moving and dignified short film was made to illustrate the lives of the 20 deafblind people and their families who were its focus. The findings from this insightful report are summarized for us here

Deafblindness

A recent survey of Bangladesh indicates that 5.6 percent of the total population has been identified with a certain form of disability. Some have multiple disabilities while almost half have severe and profound disabilities. The scenario reflects an unfathomable picture of what makes up these multiple disabilities.

And somewhere, hidden, is a notable proportion who

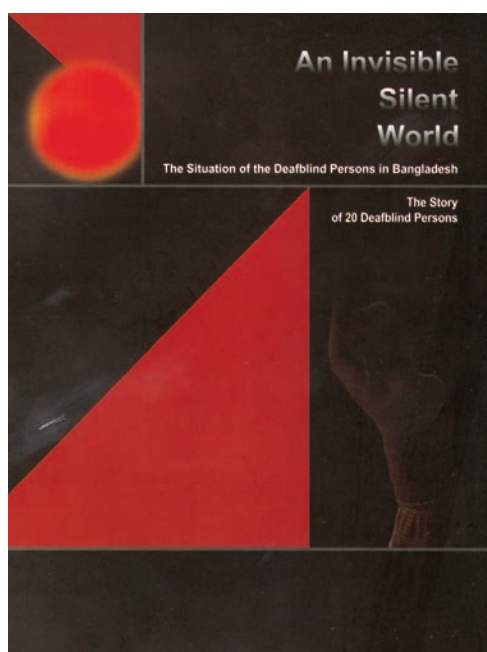
would be recognized as a deafblind in many countries worldwide. Unfortunately, this group is completely unfamiliar and absolutely invisible to the people of our society. To them life means nothing more than a deadly silence. They can feel the presence of a human being or any object only if someone or something touches their body. The only way to communicate with a deafblind person is by touching their body. Under such circumstances, a family with a deafblind member normally does not know exactly what to do to combat such vulnerability. Most of the parents of a deafblind child are totally confused and perplexed when thinking about the future and what it holds. Finally, there is a presumption that any desire, or expectation of accomplishment, as for other children, is simply not an option for anyone who is deafblind.

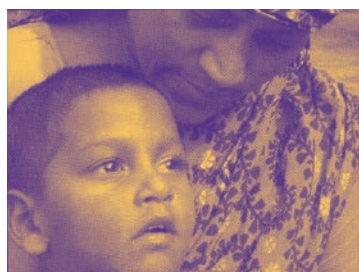
Deafblind people in Bangladesh

Recognition, or even the

acceptance of the existence of deafblindness, in the context of Bangladesh is almost absent. No exclusive step has so far been taken to identify deafblind people in the country. Neither has the issue been discussed in the newly introduced disability law in the country. It has not even been prioritised in national policy matters. Government development organizations appear to be unaware of the possible prevalence of deafblind people, as well as their existing condition, in this country. No particular intervention has ever been demonstrated by the disability organizations to meet the challenge of deafblindness and so they are not included in their on-going programme activities. Also, the recently conducted "Disability Prevalence Study" has not been designed to include the prevalence of deafblind persons in the country.

However, it is presumed, from an international source, that 0.04 percent people, among the total number with disability, are subject to some





level of deafblindness. But this ratio is neither suitable nor appropriate for a country like Bangladesh where the mortality rate of children with disability is much higher than the mortality rate of other non-disabled children. In this situation, it would not be surprising to predict, or expect, a shorter life span and as a result a situation where deafblind children are very low in numbers indeed. However a recent disability survey reveals that multiple disabilities in Bangladesh are about 10.7% of the disabled population. In this context, the possible fraction of people who might possibly be affected by deafblindness can be assumed to be an approximately one-tenth (70,000) out of 780,000 among persons with disabilities.

Alarming results

To accomplish this study, a couple of rehabilitation workers have been employed in different parts of the country. It has identified almost 57 cases of deafblind individuals within a very short period. Out of those cases, 20 individuals have been documented, witnessing the condition of each individual deafblind person through empirical visits. The purpose was to determine the underlying perception of deafblind people prevailing

in the society as well as to determine the possibility of organizations working in that area. The situation observed in all these areas was, in two words, simply alarming. The experience of that observation demands and firmly requires a concrete and coordinated strategy and prudent solution to the existing situation. However, the story of these 20 deafblind individuals will definitely be a wake up call for all of us engaged in addressing the needs of persons with disabilities in a country like Bangladesh. But what is more worrisome in this regard is that if, and when, the real and an in-depth scenario is fully revealed, we will be facing a far worse situation.

Identification of deafblind people

A number of organizations are working in the country for the improvement of the lives of persons with disability. These organizations have good access to providing information about those people. By contrast, it is difficult to find a single organization that can offer information of any kind about the existence of deafblind people in the country. It simply indicates that the disability organizations, as well as rehabilitation workers,

lack adequate knowledge to collect any information on deafblind people. The training to improve the capacity of rehabilitation workers has overlooked deaf blindness in their prescribed curriculum. Any people who have already been identified have been included into the multiple disabilities category.

Condition of a deafblind person

Most of the deafblind people identified through this study are aged between 3 to 50 years of age. Though, information about a deafblind person over 90 years of age is also reported. The condition of these deafblind people is either

“...a recent disability survey reveals that multiple disabilities in Bangladesh are about 10.7% of the disabled population”

severe or profound. A few of them have some hearing sensation but that is also recorded as insignificant and of no use. Most of them have either low or tunnel vision. Both the conditions make balance very difficult. Usher syndrome is a disability, which affects a person initially with a hearing impairment and finally leads

“A third-world country like India has set up a glowing example of how to begin to triumph over deafblindness.”

to a visual impairment. These two severe combinations ultimately make a person deafblind over the course of time. Those who have lost sight and vision before the age of three years of age, life has nothing to expect except a deadly silence. Such silence and loneliness create depression, pain and (sometimes) violent behaviour in a person, which can easily be sensed by those who know them well. It occurs because of their own limited opportunity and capacity to express themselves; even to pass on their feelings of agonising loneliness to anyone. Many of the deafblind persons who have been identified also have other kinds of disabilities as well as deafblindness. Some of them are also the victim of cerebral palsy, which results in a variable range of physical challenges including balance problems and poor motor skills.

This is a complex situation where a person cannot see or hear anything in the environment that others

take for granted. They have darkness. The meaning of life, death or any loving relationship carries no meaning for them. Their inability to move freely makes their body gradually numb.

Deafblind person, parents and family

Among the identified deafblind people, most of them hail from a very poor family background and some from an extremely poor group. Affluence, wealth, prosperity, or any privileged circumstances do not mean that a child's physical impairments can be reversed. Such families have the possibility to spend money with the intention of getting a better result or improving the present condition. But, for many, any development or improvement of the present condition is seen as an unattainable goal. The cry and repentance are similar to every class of people. In their quest to bring changes in the existing condition of a child with deafblindness, many poor people have been financially ruined and have

had to become day labourers. Their only hope, and expectation, was that their efforts could have changed the existing condition of the child!

Services and treatment for deafblind people

The people in our 20 case studies have already experienced very different treatment from each other. While some forms of treatment are tranquil others are disappointing and generate more frustration among people. Many families could not know of, or notice, the problems soon after the birth. The way the deafblindness has been found, initially, for many families, has been through observing abnormal behaviour over the course of time. Initially, a family could have sensed the hearing problem in a child but had never paid any attention to it due to inadequate knowledge and ignorance. Consequently, a doctor has never been consulted. Vision problems in children, in most of the cases, were noticed



between 3 to 10 years of age. Primary consultation was done by a village doctor and later in a local eye clinic. Many families brought their children to a city hospital or clinic for better treatment but none of them experienced any real change so far. Many poor families, ultimately, had to place their children's treatment in the hands of a local traditional healer. Some of their healing procedures are shocking as well as traumatizing. Practice of maltreatment was also recorded. A deafblind child with cerebral palsy was advised by a local physician to receive a sedative every time he gets agitated or squirmy in order to make him quiet and calm. Services for a disabled person in the country are available, even if they are not high quality, but the idea or even a thought of getting any treatment for a deafblind person in the country is just like chasing a mirage.

Possible remedy of deafblindness

Is there any possible remedy or support for deafblindness? It is a vital question for people worldwide. Many nations have already made good progress in the area but the issue still creates a perplexing situation for many of us in the developing world. History gives us evidence from the 17th century of deafblind people in France. Many advanced and developed

countries during 18th and 19th centuries followed. Comparing our advancement with developed nations might be a dream but should never be viewed as an impossible task. A third world country like India has

“The only way to integrate deafblind persons with family and more broadly into mainstream society is to develop their communication skills along with their parents and other family members.”

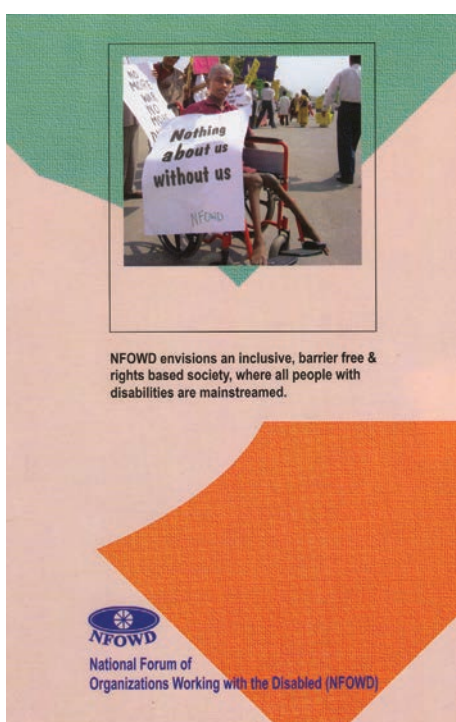
set up a glowing example of how to begin to triumph over deafblindness. India proves that if there is a good intention to do something then it is not only possible but also achievable through concerted effort. Deafblind people should not only “survive” during their lives, they should be able to contribute to the national life. Information technology has helped minimize the impact of many disabilities and has also helped

overcome many barriers for deafblind people. In recent times, in many parts of the world, deafblind individuals are achieving at school and competing with others to get into the higher education system or into a trade in order to establish themselves properly in the society. Many deafblind children from poor families have learnt communication skills to converse with other family members to express his/her needs, demands, desire and expectations.

Sign Language and other forms of communication

Sign language helps a hearing impaired person to understand and communicate with others. This is possible because a hearing-impaired person can see others and follow that accordingly. On the other hand, deafblind people can communicate with others only with the help of touch. A person mildly or moderately affected by deafblindness may follow an enlarged alphabet or symbolic forms, as a tool of communication. If a deafblind person's communication skill is developed, he can easily overcome other impediments by using Braille or other tactile means. Braille, with the computer, has helped to minimize many constraints regarding communication and education for visually impaired persons. Using

Deafblind people in Bangladesh



Braille is also applicable for a deafblind person to minimize communication, education, and even employment-related problems. ICT is opening up new horizons for deafblind persons. The only way to integrate deafblind persons with family and more broadly into mainstream society is to develop their communication skills along with their parents and other family members. If a deafblind person is cognitively unimpaired he will develop the skill of communication quickly and would put huge efforts into the challenge. Sadly, as no information or services are available for deafblind people in Bangladesh, there is not a single word of consolation to offer the family of a deafblind person. But now the time has come to change the existing perspective. There is still a ray of hope as advancement takes place for deafblind people in developed and developing

countries – and even in our neighbour – India. We hope these examples of positive work will definitely give people hope and encouragement to go forward.

Conclusion

Demand for human rights worldwide now has a single voice and has become an undivided struggle. The issue of a disabled person's rights is reflected and implemented in many of the activities of organizations globally. Being born a human being, but being refused and rejected from taking any real fulfilling part in human life has been, as if by predestination, the fate of every deafblind person, in a country like Bangladesh. The foremost challenge of any human community in each society is to stand on a single commitment to bring a positive change in their lives. A deafblind person and his family do not know the skills and knowledge about how to communicate or understand each other in a natural way. This responsibility should be ours – to give them their basic rights by assisting them in every way we can. This problem is universal and not the single problem of one particular society. Each society needs the involvement of government, development organizations and organizations working for human development (and particularly those who are

committed to bring changes in human lives) to ensure success.

Dealing with a child with deafblindness is possibly the most challenging and complicated of all the disabling conditions. To handle such a problem, we must know the strategy and mechanism to resolve the situation with extreme zeal and endurance. At the dawn of 21st century, with the evolution of sophisticated communication tools and successful advancement of information technology, problems have become easier to manage.

So the time has come to unite and act to combat this sensitive reality. All these abandoned and anonymous deafblind babies, children, young adults and older people in Bangladesh must be identified and provided with proper attention and care. If we do not start it today, it will be too late tomorrow. With cooperation, support and determination we can definitely triumph over such a unique crisis.

The report is called **"An Invisible Silent World"** – the situation of the Deafblind persons in Bangladesh. The Story of 20 Deafblind Persons.

Published January 2006 by NFOWD (National Forum of Organisations Working with the Disabled and Handicap International and supported by DFID – UK.



No sound is wrong... music is communication

Birgit Kirkebaek and Cathrine Lerwig

The background for this article is an applied research project on the establishment of shared experiences through improvisation. The project was a co-operation between two resource centres: The resource centre for children and youth with multiple impairments (with the Danish acronym VIKOM) and the resource centre on congenital deafblindness (with the Danish acronym VCDBF). The project was concluded in late summer 2005.

The article argues that an aesthetic perspective based on Colwyn Trevarthen's and other researchers' recognition of the connection between music and communication may help many of the children with severe impairments. These are the children who are today treated with strategies inspired by behaviourism – or whom we work with strategies which are exclusively directed towards cognition. The argument for the reasoning chosen is that an aesthetic approach includes emotional aspects and combines emotion and cognition. This, however, requires that all expressions are noticed and taken seriously. The article is based on a case study on a young man, Jon, 16 years old. He is blind, but has residual hearing. The article is constructed in a way that it first provides a from-outside-perspective on the interaction between Cathrine and Jon, such as it has been presented through analyses of video recordings, and thereafter the artist's own experiences from an inside perspective, stating how the interaction

with Jon was experienced and the reflections which this made way for.

The "aesthetic" and the "bodily"

"The lived body" is an expression applied by the French philosopher Maurice Merleau-Ponty. It means that "the body is an expression, which cannot be separated from what it expresses". Meaning and participation are main concepts when we speak on the basis of an aesthetic paradigm. Merleau-Ponty's "perception of the lived body as our original and meaningful way of accessing the world" may also contribute to the understanding of what happens in the sequences of interaction which develop between Cathrine Lerwig and Jon when they improvise. They create a space – a lived space. "The lived space," in Merleau-Ponty's sense of the expression, comprehends both the physical, the bodily, the psycho-social and the musical space.

Merleau-Ponty's point is that "we are bodily present in any perception", and hence it is not possible to

take a distance from this even though the world seems different for those directly involved and those in the audience. Merleau-Ponty highlights the body as an experiencing subject – in other words as a silent witness. "The silent witness", which Merleau-Ponty speaks about is the lived body, which means not only the experienced body, but the present, social and meaning making body, as opposed to the purely biological body. The most fundamental condition for perception is our body, or, as Merleau-Ponty expresses it: Our body is not in the time, it inhabits space and time. So basically we are our body, but the body may also perceive itself, which is a prerequisite for the instrumental idea that we have a body", as the Danish researcher of music theory Svend Holgersen writes.

Merleau-Ponty describes the meaning making relationship between the child and its environment as intentional. He has a particular category for movement, which he calls locomotive intention. Intention has something to do with meaning making

through interaction. For Merleau-Ponty the body is the original unit for meaning making. The world is not it in itself meaningful, but "it is meaningful to us due to our bodily existence and access to the world." Merleau-Ponty thinks that we see things in their entity and not only in their actually featured part. The lived body, for him, is doomed to make meaning – in other words, it just cannot be ignored.

When Cathrine Lervig and I myself have a focus of the innate rhythmic pulsation, of non-verbal communication and the child's effort to create meaningful coherence and flow, an aesthetic paradigm is its basis. A major point of this aesthetic is that the product is completed by the co-operation of the Other – in other words that nothing is fulfilled before it is seen and interpreted by an Other.

An outside perspective on Cathrine's interaction with Jon

When one analyses the video recorded interaction between Cathrine and Jon, a lot of questions emerge. What do the constantly occurring head movements which Jon makes mean to him? Which experiences do they give him, and which emotional expressions may we find in his behaviour – and in that of Cathrine? What happens between them? And how does the artist encounter the individual, with whom she is going to meet for the first time? The encounter had the following development (described in greater detail in the Danish book "No sound is wrong").

Jon sits in a wheelchair opposite Cathrine. He moves his head from side to side. Cathrine and Jon start by holding hands. Jon then lets go of Cathrine's hand and makes sign of taking off his shirt. Cathrine tries to join him by singing, in the rhythm of Jon's head movements. Here there is a break. Jon gets a grip of his own hand and briefly stops moving his head. He produces deep sounds, as well as a kind of spitting sounds. Cathrine imitates Jon's small sounds.

sings in the same rhythm as Jon moves his head. She adds something new to his movements; the sound of her voice. There is a break. Jon seems to be listening attentively. Cathrine lays her hands on his shoulders. Jon explores her hands briefly and then puts his fingers in his hands for a short while. Jon swings his head intensively and murmurs. Cathrine follows up with a very wavering voice or vibrato. Jon is indeed attentive – he is very participating and very



She continues with non-sense talk and sings again. Jon now dances with his fingers. He seems to obey to his own basic rhythm. Cathrine seems to be seeking and a bit insecure. Jon turns his head rhythmically and "dances" with his hands/fingers and produces small sounds. Cathrine awaits Jon's initiatives and tries to answer his sound productions, and she answers these and tries to take Jon's hand. Jon withdraws his hand, and Jon's teacher suggests that Cathrine touches Jon's arms and shoulders in stead. Cathrine follows up on this, and Jon accepts this way of touching. Cathrine

listening. There is a close head-to-head contact. Vibrato in a low pitch in accordance with Jon's proper sounds. There is harmony and shared experience through vibrating sounds. Then there is pause and consideration. Jon sits totally quiet without swinging his head. Cathrine starts to sing in a higher pitch tone, but still has the deep, "raw" sounds as her basic rhythm – the same rhythm as Jon's head movements. Jon straightens up, strokes his forehead and again swings his head from side to side. Cathrine's hand is on his shoulder. Now Jon begins to explore her hands, at first with his left and then with his



No sound is wrong...

right hand. He briefly holds her hand with his right hand. Cathrine then approaches him with deep, strong and vibrating sounds. Jon listens again. Cathrine's initiative is dramatic. Jon still holds Cathrine's hand. Again he lifts up his shirt – several times. What does this mean? Jon puts his fingers in his mouth, listens, with his face towards Cathrine and again swings his head. Cathrine puts her hand against his shoulder. There is an exchange of murmuring sounds. Jon has his fingers

intentionally. However, what struck me most was how Jon being deafblind confirms and reconfirms his communication with Cathrine. In the beginning Jon is in his own basic rhythm. As Cathrine adds a "leading part" to this basic rhythm with her voice, Jon becomes attentive and participating. It supports him that she touches his shoulder, but as he uses his hands and fingers partly for dancing and partly for exploring Cathrine, he does not want her to hold on to his hands. As I see it,

which Cathrine confirmed that at Jon independently explores her hands and wants to know who she is. If she is hot tempered and "dramatic", he will, by tearing off his shirt, manifest that he, too, is hot tempered and "dramatic".

The episode described and our interpretation of it is indeed what the Norwegian psychologist understands as an aesthetic paradigm. It has to do with moments of aesthesia, such as the Norwegian professor of musicology Jon-Roar Bjørkvold describes it. When Cathrine adds something new to Jon's expression, and when he responds to it and considers her suggestion, they co-create a new aesthetic expression, which contains something from them both.

What Jon uses in his communication are the head movements from side to side and his vocalisations: In my "from the outside" observations Jon's sounds and the use of the hands a major role, just as his unreserved acceptance of Cathrine must be highlighted as something special. But also the head movements, I think, are something much more than stereotypes and introvert activity.

The head movements have very different meaning and are used for different purposes:

- they set a rhythm of rest which has a sleep inducing character, he is relaxed and on his way to sleep.
- they are used as a personal flow, which make his world coherent.
- they are used as a rhythmical instrument, which sets both the rhythm



in his mouth. Harmonised murmuring sounds head by head. Jon yawns. "Have you had enough of this now?" Cathrine asks. Jon reaches his hand towards her. Again their heads are touching. Jon lets his head fall down on Cathrine's arm. For a long time they sit like this. Jon stretches out like after a good sleep. Thank you for the class!"

The things, which caught my attention, were partly the fact that Jon tries to take off his shirt and partly the effect Cathrine's vibration has on him. Finally I was very absorbed by Jon's use of his hand movements; they seemed to be used very

the dance of the hands is a way of sharing the experience with Cathrine. When she confirms him by adding something new (the sound of her voice) to his basic rhythm (his head movements), he then re-confirms her by adding the dance of his hands. Together they explore the "head-by-head" effect of the vibrations. They share the experience. Perhaps the attempts to take off his shirt are a way of expressing enthusiasm – an excitement – which may be compared to the reaction in a soccer player when he scores a goal. But it may also be considered as a re-confirmation of the dramatic expression with

and the tenderness or ferocity in the expression of the piece of music.

- they also set the pace and dynamics and are parts of the shared flow, which he co-creates with Cathrine.
- they are used to provide the particular sensory experience which it gives when you move the head from side to side according to a sound source with different rhythms – it is a kind of amplification of which he himself is in control.

When his head movements stop, he signals: I am responsive to the new things you will bring to me.

His hands also seem to be used for several different purposes:

- Jon calls on, accepts or rejects Cathrine's hands and thus signals both limits and an accommodating attitude.
- Jon explores Cathrine's hands and finds out how she is.
- Jon uses his hands and fingers as an instrument and plays on Cathrine's hands as if they were the keys of a piano.
- Jon uses his hands to communicate frustration: He presses his finger into Cathrine's hand, and he hits himself. He also protects himself or prevents himself from doing things by sitting on his hands.
- Jon uses his hands to pull up his shirt and thereby signals receptiveness – or he uses them to feel his stomach and signalise "this is me" – or to pull up his shirt and bite it, perhaps as a sign of insecurity or need for a break?

Jon's vocalisations are varied and manifold. If I close my eyes and listen to the sound track of the video recording, the pattern which Jon and Cathrine create together seems very melodic. They tune in to each other and harmonise their sounds. With the eyes open the sounds must be perceived together with the movements in Jon's head and hands underlining the emotional value of the interaction in general. Jon wishes to communicate in a musical way with Cathrine, but he also decides for how long and how he wants to participate.

The "from within" perspective – Cathrine's experience of the interaction with Jon

In the nature of free improvisation there is an attitude to the surrounding world, which is quite basic to me. There is an openness, a curiosity towards the other, an equality in the "togetherness", a way of communicating, a way of being oneself; a way of being oneself in the presence of others. Improvised music is co-created on the spot. The individual person's characteristic expression has its place within an entirety. When we who are improvising musicians play, we are on the lookout for opportunities for ourselves and for each other. We search for the presence in the particular moments, which develop among us.

We are all born with musical resources and have the ability develop those in an interaction with other people. Using improvisation

has proved to be fruitful in the attempts to work with persons who are born deafblind and have no spoken language.

In the research and development project mentioned I have given 10 solo classes to a total of 6 children with no spoken language (3 had congenital deafblindness, 3 had multiple impairments).

My very first impression of Jon is that he uses his voice in very varied ways and very expressively. During the first class with Jon we were going to learn to know each other and in a new way.

I met Jon without words, but with *my voice*, and even though Jon had never met anyone like me before, I noticed a readiness, a curiosity, an open mind and an ability to enter musical interaction with me. During our 10 solo classes moments of presence became more frequent and they lasted longer.

Jon expresses himself in very subtle ways with his voice. High pitch, opera like sequences, deep murmuring sounds, sequences where he uses his voice like in speech, with rhythm and toneme as in speech, just there were no words. Jon expresses many aspects of himself with his voice. He has a wide scope of emotions, and he uses it, to express himself. He definitely has "two strings to his bow".

In the middle of the third lesson Jon listens intensively to a deep and quiet song which I am singing. Suddenly he sings some high shrieking sounds while his head moves from one side to the other. As I imitate the high pitch



No sound is wrong...



tones by altering between a high and a dark voice, it becomes clear to me that he wants me to stop making the high-pitched sounds and only sing the deep sounds. It seems that the high pitch – introduced by him – surprises him and disturbs him; it “seizes” him – invades him.

I have met this before with other deafblind persons. And afterwards it seems that everything is forgotten – all the things we were doing. I am persistent and continue doing what I was doing before: with the rhythm, the body and with the song a kind of bridge is constructed across the disruption. This helps the person return to what we were doing, return to the present. With Jon this bridging works and we may continue our interaction.

If as a partner one does not try to maintain the shared interaction, it will be interrupted and one has to start again somewhere else. Here it is the uniting quality of music, the shared flow,

which helps us through. By working with a person like Jon over a longer period of time I have experienced that the disruptions coming from within have changed. It is as if the bridge – the fact that I hold on to what we share – sheds new light on the disruption and offers some kind of awareness which may help the person to learn to know and to control the disruptions.

Listening to Jon’s voice in his everyday life, he varies a lot in the ways he uses it. I interpret his leaps partly as emotional disruptions from within, and partly as Jon’s comments to the stream of impressions coming from outside. At the bottom of each expression there is an emotion. Thus we here talk about emotional leaps. From my proper work as an improvising singer without words, I know that these jumps are very emotionally requiring. The reason is that one tries to pay attention to everything which happens

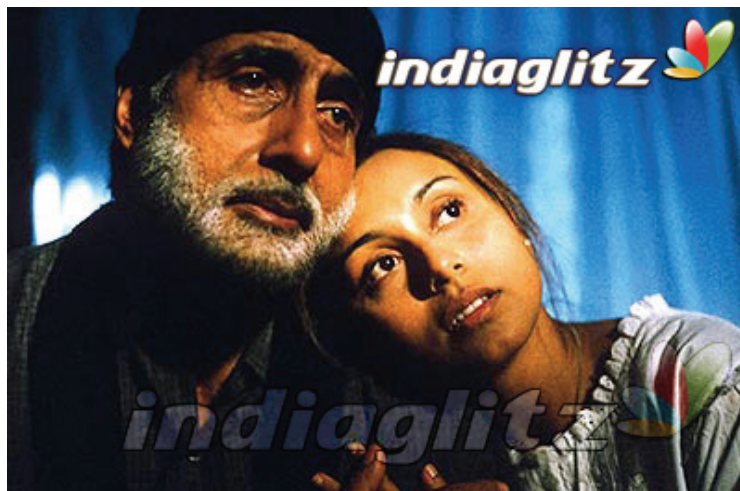
and to comment on it without being grounded. In this way one is swept around in one’s own emotions. This is not purposeful.

I consider the basic flow in music, music’s ability to bridge gaps between different states of mind and create smooth transitions is an important tool for any human being. We practise a lot of this when we speak to each other. A person like Jon most certainly needs these skills, among other things because he has to be able to readjust all the time. He seems to be able to do this in musical improvisation.

This article has been printed in **Doevblinde Nyt**. The article is a short version of their book with the same title. Birgit and Cathrine have referenced this article and can be contacted on –
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Black – seeing is believing!

A response to the blockbuster award-winning Bollywood film, *Black*
by our film correspondent – more usually known as Akhil S. Paul,
Director, Sense International (India), Ahmedabad.



In my 30 odd years of watching Indian cinema, I have never come across such an inspirational and strong movie. "Black" is even more special because it is about a "deafblind" girl. I feel that this movie is going to lead a big campaign for making people aware about the needs of deafblind people, their families and teachers who work with them.

The movie touches upon every aspect of life – childhood, family's struggle of having a deafblind child, sibling rivalry, people's perspective and attitude and transition of a young girl to womanhood. The movie goes to show how a subject this difficult can become such a brilliant screenplay and I think that's the professionalism and craftsmanship of the master storyteller- Sanjay Leela Bhansali.



Michelle McNally (Ayesha Kapur/Rani Mukherji), is a deafblind girl born to an Anglo-Indian family. Michelle is a bright and intelligent girl but with no one to communicate with, lives in a world of black silence. This leads to frustration, which results into mood swings and violent/destructive behaviour.

Debraj Sahai (Amitabh Bachchan) is teacher of deafblind children who is sent to Michelle's home to teaching her. What we also realise it that he is also an eccentric and alcoholic. The first encounter with Michelle makes Debraj realise that the mannerisms of Michelle can be dealt with only by being aggressive and at the same time with tenderness. There are many challenges and hurdles on the way but Debraj succeeds in teaching the first word to Michelle and then the language. Debraj shares his dream of Michelle going to a university with non-disabled students. But, by this time, Debraj is declining and is attacked by Alzheimer's disease and he slowly forgets everything- all words and their meanings too. Now Michelle becomes his teacher!

I congratulate Sanjay Leela Bhansali for his imagination and interpretation of Helen Keller's life. There is no doubt that Rani Mukherjee

“Technically speaking, from the point of view of deafblindness, Rani and Amitabh have really done justice to the roles by learning and using correct sign language, gestures and postures”



(Michelle) has surpassed all performances and without even a single word, and only expressions, she has set new benchmark for her colleagues in Indian cinema. Similarly, Amitabh Bachchan (Debraj) has proved that he is still number One by very beautifully portraying the role of the teacher of Rani. I am sure that he will be remembered always for this performance.

Technically speaking from the point of view of deafblindness, Rani and Amitabh have really done justice to the roles by learning and using correct sign language, gestures and postures. The overall layout of the film is brilliant. All the actors, especially the child artist Ayesha Kapur, left people speechless with her brilliant performance of young Michelle.

“There is no doubt that Rani Mukherjee (Michelle) has surpassed all performances and without even a single word, and only expressions, she has set new benchmark for her colleagues in Indian cinema”

Focusing on the Fundamentals:

A Person-Centred Approach to Programming

Sharon Elliston follows up on the article in the Review last time with a progress report on exciting work in Canada at the Independent Living Residences for the Deafblind in Ontario

When Independent Living Residences for the Deafblind in Ontario (ILRDBO) set out on a journey some 18 months ago, it had one clear objective in mind: to raise the bar on programming by placing Residents at the centre of its service. A simple goal one may assume since individually-tailored programming has been a mainstay of the agency since its inception in April, 1989.

But nothing could be further from the truth!

This lofty project, funded by The Ontario Trillium Foundation, has come around full-circle and involved the coordinated effort of countless staff, volunteers and community resources that shared information, sat on committees, participated in pilots and put in extended hours, well beyond “normal”

requirements, to see this project to fruition. Beyond that, the agency also put in place a full-time, contract Project Coordinator and secured outside help to assist with developing and promoting the Program Module – a product of the new Service Delivery Model – to internal and external stakeholders. As a commitment to quality assurance, the agency has also hired a Manager of Resident Services, a new position created to ensure consistency and adherence to the new Service Model by all staff.

With the Program Module set to print by the end of the month, and the new Service Model already in place, the Agency has taken its programming to an even higher level.

Throughout the project,

the team has used “focusing on the fundamentals” as its credo—that is getting back to basics and what really matters. Already establishing that the focus should always be placed on the Resident, the challenge was to introduce Person-Centred Approach (PCA) programming that made full use of imagination, intervention and independence. It appears the agency has also met this challenge: PCA programming encourages Residents to dream and imagine the possibilities; ILRDBO trained Intervenor will support Residents to make their dreams a reality; and, together, imagination and intervention encourage Residents to reach their fullest potential as they move toward greater independence.

PCA programming puts the Residents’ preferences, desires and choices at the core of each individually-tailored program. To make the programs as inclusive as possible, a Multi-disciplinary Program Team is now involved in the goal-making process. The team meets every 18 months and is comprised of a number of people and groups linked to each Resident, including: family, guardians, advocates; community, vocational and



medical sources; and ILRDBO staff. It's the role of the team to support the Resident to communicate their needs and desires and to ensure that the Resident's wishes are followed. However, if a Resident is limited in expressing their needs, the team works together to represent him or her.

Once the service process is redefined, it is only natural to document processes and make the data accessible to staff and other service providers who might benefit from the information. The result is a comprehensive Program Module binder which is the highlight of this project and outlines procedural and best-practices information for ILRDBO staff and Intervenors who deliver services. The module is organized into three components:

- **Resident Program Portfolio** – contains detailed information about the various tools used to assess, monitor and review Resident activities, progress, goals, achievements and challenges. This ensures that programming is consistent and uniquely tailored to each Resident.
- **Service Tracking** – tracks the service provided, and in turn, ensures that the activities and programs undertaken enhance the quality of life for our Residents and gives evidence of services to funding agencies.
- **Service Evaluation** – indicates whether program requirements are met and whether the goals are meeting the needs of the Residents.

This then provides data to the organization, which allows for future recommendations on the service delivery model.

Having come around full circle, where before the pilots were done to guide the development of the Program Module, the module is now being sought as a reference and guide to ILRDBO best-practices and is being used to train Intervenors on the facilitating the new Service Model.

For further information about the Program Module, please contact ILRDBO at (905) 853-2862 or email: admin@ilrdb.ca.

Full participation in education for children with acquired deafblindness – some ideas to support good practice

Leela Agnes, of the Holy Cross Service Society, India, shares some ideas after meeting and talking to colleagues and students at schools for the blind. She has also carried out a study at the School for the Blind in Thiruchirapalli to find out the prevalence of hearing loss.

Disabled students studying in a special school for the blind, who get a hearing loss in the later stage, are not getting adequate training and support on time from the special educator. This is because blind school special educators are unaware of the condition and requirements

of hearing loss. Special educators are frustrated with the deafblind condition and this leads them to avoid the deafblind children. This avoidance hinders full participation in the classroom instruction for the deafblind children. This may lead the deafblind children and young people to think that they are

too dull, too bad and too mad for the educators to take their education seriously. We have to realize that the needs of acquired deafblind pupils can be neglected in special schools for the blind.

Educational needs

The most important idea to have in mind is that

deafblind pupils have the same educational needs as the other pupils: to learn the same content, to socialize through interaction both with peers and with adults, to feel secure and self-confident. They also need to develop their cognitive, social, educational and personal capacities in a harmonious way. Lack of awareness of the specific educational needs of deafblind pupils on the part of teachers, blind peers and deafblind students themselves may lead to low academic achievement, emotional isolation and social exclusion.

“Like all other children, deaf blind children have the right to read and write Braille in the regional language, and thus have independent access to knowledge and information.”

Communication Power

The ability to communicate effectively is at the heart of the process. Without the ability to communicate in a variety of situations that are critical to them, children will find the task of making sense of things an impossible one. To function effectively in their family, their social groups, their classroom and their community, children need a kind of communication power – the ability to perform effectively in communication encounters. Communication is the basis of sociability and an essential

part of being a human being. Communication must be viewed as an integral part of total development of human beings. Children struggle to discover a system of beliefs about reality, self and others. Their most important tool for discovering beliefs is communication.

Impaired hearing easily causes breaks in communications. Persons who have impaired hearing may run into situations where the information they receive is inadequate and it may cause them to be excluded from information and communications. This may result in shyness, withdrawal and a proneness to paranoid interpretation of messages from the environment. It may also lead to a poor knowledge of their environment. With its ignorance, prejudice and indifference, the environment may hamper the development of blind people with impaired hearing.

Like all other children, deaf blind children have the right to read & write Braille in the regional language and thus have independent access to knowledge and information. If deafblind students get fewer opportunities to read and write Braille, then they face problems. For example they may develop an inability to put their thoughts into writing, or provide answers that lack a sequential process. They may find that they are unable to present the content in a logical order or their problems in developing vocabulary skills are emphasised. There may also be an obvious discrepancy in oral and written skills.

Self worth and Stress

Blind people with impaired hearing can have a lower self-image and lower level of well-being compared to blind hearing people. Blind people with impaired hearing tell us they experience fear; fear of failure, fear of people, fear of new situations, fear of sudden noises, fear of being slighted and avoided. These fears make them to suffer in their daily life.

Blind people with normal hearing can be spoken to and understand what was said in the presence of other sounds. But blind people with impaired hearing often can not do that. Even when doing a simple task, blind people with impaired hearing must stop in order to concentrate on what is being said. The result is more stress.

A major continuing problem is that too often people do not recognize their hearing is deteriorating. While they can hear many sounds, they lose the ability to hear those tones that allow comprehension of the spoken word. To make it clearer, hard of hearing people may hear all the words of the joke but yet not comprehend the nuance or secondary meaning of the words and therefore do not get the joke. The inability to get the full message adds stress to deafblind people. Hence people who are working alongside and with deafblind people should understand the emotional factors and effects of being hearing impaired. Teachers should be sympathetic. The teachers should let them know that the nature of their difficulties is understood and

that he is keen to help the student make progress.

Deafblind children need special provisions and tailored intervention programmes to compensate for the consequence of deafness. This implies early diagnosis, audiological care, medical care, the provision of communication technology, etc. An individual approach is essential to examine the child's specific difficulties and to provide an appropriate teaching programme. A deafblind child must experience an excellent quality education, which offers the opportunity to achieve his potential. School management and teachers should have cooperative collaboration with specialized educational support services to provide adequate conditions for deafblind students to receive quality education.

Recognizing the needs of acquired deafblind students studying in special schools for the blind, the following are the responsibilities of the special educators in order to contribute to a happy school atmosphere for deafblind students.

Special educators

- must be able to draw on knowledge and understanding of acquired deafblindness and its effects on communication and language and they should communicate this in every way possible to blind pupils. They should promote deafblind awareness.
- should recognize the need to work towards achieving independence

“An individual approach is essential to examine the child's specific difficulties and to provide an appropriate teaching programme”

for the deafblind pupil. They should develop approaches which will foster the development of self awareness in deafblind students with regards to their situation and needs, leading to self-advocacy.

- should make their role clear in order to establish realistic expectations.
- should be aware of their own need for constant updating of professional knowledge and skills.

It is necessary to inform and train all the teachers in the school about the needs of deafblind students and promote discussions to meet these needs.

Ear problems and hearing loss among blind students

With the help of 142 blind students, studying in school for the blind, we conducted an ear examination and hearing assessment. The result of hearing tests showed 66 students had slight hearing impairment (26-40dB) and 5 had moderate hearing impairment (41-60dB). Hard wax, otorrhea, retraction and bulging are the causes.

| Ear problem | R.E | L.E | B.E | Total |
|-------------|-----|-----|-----|-------|
| Wax | 9 | 10 | 24 | 43 |
| Otorrhea | 3 | 3 | - | 6 |

Among 24 students who had wax in both ears, 13 are having slight hearing impairment and one with moderate hearing loss. Four students with CSOM are having hearing impairment. Otitis media can cause deterioration of hearing. If this is not treated, bone erosion increases which can lead to complications, such as deafness. Hearing impairment due the ear problems are preventable. But due to lack of awareness some blind students are facing these problems.

Students who suffer with ear problems like hard wax, blocked ear, pressured ear, etc., can face a problem in the classroom when the teachers may not make their speech clear and directed towards the students. Students with such a problem will have to put more effort into listening to the speech of the teachers, which is exhausting and hinders concentration for longer periods. Failure to receive clear comprehensible speech and a lack of ability to concentrate hard for even short periods creates poor long-term academic results.

Leela Agnes
Holy Cross Service Society

Breadmaking – a masterpiece for the mind and body !

That's how GRUPO BRASIL'S latest project PÃES SENSACÃO has been described! Making artisan bread in a real situation in the community with a master baker in charge is the current challenge for deafblind people. Márcia Storino, herself a Baker and Instructor of the bakery students tell us about it.

TRAINING: Apprentice

JOB: Bakery helper

BRANCHES: Industrial bakery, making artisan bread

WORKFORCE: Deaf, deafblind, multi-sensory-impaired people, young people and adults from the community and their families.

The bakery of Grupo Brasil – “Pães Sensação” – “Bread Sensation” was initiated in February 2005. It is located at AHIMSA, in Vila Mariana – São Paulo.

It depends on the support of volunteers, parents,

professionals and friends of deafblind and multi sensory impaired people in the community.

Our first year at the bakery has been successful and we know this because of all the comments and testimonies of the people that are involved in the planning and setting-up of the project. Also because of the development of our balanced bread production – to produce bread that has character and interest and is delicious!

Some have said that the bakery is “a masterpiece for the mind and the body”. The manual work requires the whole process to be thought out, including the production line of the bakery, to make it work for the deafblind people and the non-disabled alike.

According to some mothers

who take part the domestic tasks that sometimes can be repetitive and boring at home become LEISURE when done together with the group of apprentices!

For those that know nothing about cooking but are interested, the bakery can be the beginning of new learning. To work with bread it is necessary to go through all the stages of curricular learning and this craft is considered a branch of gastronomy.

Being among the group of apprentices offers an opportunity to have fun together while working hard during the 6 (six) hours of activity. There is no perception of the existing differences in the group during the stages of preparing breads, cakes, biscuits, etc...

The apprentices get amazed with their capability to learn new things, tackle situations that they have never met before or rediscovering things that they had forgotten. They are able to make friends and really get to know people.

As this activity is a profession recognized in the law – “bakery apprentice” – for the deafblind, the multi sensory impaired and others each day their development



is a personal surprise. There is no such thing as disabled due to the sensory loss. They all can do it!

We are an active community that works from Monday to Friday and at the end of the day we see the results of the work. At the end of the day we are anticipating a treat. Part of what is made is spread among the group and can be taken home to their family and friends in order to taste what the apprentices have

made during a pleasant and expanding working experience!

What is important for us is the recognition of the production capacity that each apprentice has. Capacity that is not only equated to the ability to earn money but also to creativity. And for the apprentices before coming here there was no reason for them to use any creativity. At the bakery their creativity is built on day by day through the preparation of the

bread. And it develops!

The work is independent, complete and everyone leaves his or her limitations outside the door! The result is "always" a positive one. The atmosphere allows us to trust each other with some of the most important things in life – the exchange of "family secrets' recipes". The success of the project is down to that willingness to share knowledge and experience as well as having a workforce who enjoys being an apprentice!

DbI Strategy Review Group



Pictured here are the members of the group, left to right: Akhil Paul (India), Sergei Sorokin (Sweden), Tony Best, (Chair) UK, Isabel Amaral (Portugal), Maria Graciela Laynes (Peru)

I am delighted to report on an exciting, and very important development that will affect everyone connected with DbI.

Council has appointed a Group to review all the activities of DbI and to suggest a strategy for what the organisation should achieve over the next 5 years. The ideas for the strategy will come from DbI members and so there will be a major consultation with members and other interested people from September 2006 to January 2007.

The group will want to know how you think DbI should develop – for example, which

activities should be organised, what should be our purpose and ambition, how should we use our money, who should the organisation serve and support. Details of the consultation process will be distributed over the June – September period. The final strategy will be presented for consideration by Council and members in September 2007.

If you have any questions or suggestions, please contact the chair, Tony Best at tony.best@sense.org.uk.

Tony Best
Chair, Strategic Review Group

Meeting Mbekiseni Mthetwa and his family

Thandi Ngubane and Corrinne Pillay of the Arthur Blaxall School, Deafblind Unit make a home visit to Hlabisa and describe the benefits of working with families to share ideas and information.

The journey begins...

We started our journey to Nongoma from Durban by combi. There are buses available. However, it is much better and faster to travel by combi. It took us 4 1/2 hours to reach the town of Nongoma. From Nongoma we travelled by taxi another 30 minutes to Hlabisa, the township where Mbeki stays. From the taxi stop we walked a further 20 minutes on uneven ground until we reached the home.

The homestead

The Mthetwa homestead is built in true Zulu fashion with the main house surrounded by many other houses or "rounds" as they are called. Mbeki and his father have their own "round." This is neat, well-furnished and

remarkably clean. We slept in this "round."

The main house is well-furnished too. The kitchen has a black 4-plate stove, gas stove, fridge and kitchen units. The lounge has a television set, display unit and lounge suite. They have electricity. However, they fetch water from a communal tap. They have outside ablution facilities.

Financial status:

Mbeki's family is poor but happy and generous. They are willing to share the little they have. Unfortunately, the large family relies heavily on Mbeki's grant, his father's wages and his grandmother's pension. Despite this, Mbeki is well-catered for and the family, especially his two aunts, see to his needs.

Family relationships

Mbekiseni comes from a big, happy, loving family. The family is an extended one. He stays with his father's family, which consists of Mbeki's brother, stepbrothers, two grandmothers, aunts, uncles and cousins. (approximately 20-25 people) Mbeki is well-integrated into the family and loved by all. Sadly, Mbeki's mother deserted him when he was still very little. His father works and stays in Empangeni and occasionally goes home to Hlabisa.

Unfortunately, it was quite sad to see that Mbeki's grandmother was quite ill, recently having a stroke. The stroke has left her partially paralysed. She has difficulty eating as she has terrible throat and mouth sores. Mbeki was visibly taken

A 'round'



The main house





Meet an African family



Family members

aback by the extent of her illness. Thandi offered the family practical suggestions on how to care for the grandmother. This was much appreciated by the family. Mbeki's other grandmother was busy making grass mats. She showed us how to do this so we could teach the other children.

Meeting and talking

The family was very happy with the progress Mbeki has made, especially in relation to his acquisition of English. They were also very happy that he was wearing new glasses, which were provided at no charge by Dr. Naude.

However, his aunt was

still very concerned that Mbeki was not placed in a mainstream class of hearing children. She felt that Mbeki does hear sufficiently to cope in the mainstream of the school. This situation really concerned her. She also spoke about his upcoming operation on his ear. She was glad he was having the operation and said we must keep her updated as to when it was and when she was to come to school to accompany him to the hospital.

Community life

Mbeki is well-integrated into his community and family. He often visits the neighbouring



families. He enjoys playing soccer on the playing field.

The family was very happy that we visited their home. This home visit really strengthened the relationship between the family and us, at school. The family felt more comfortable with us and this has helped to open communication between the two parties. The family was much more willing to share information with us.

Latest developments

Since this article was submitted, we received the sad news that Mbeki's grandmother had passed away. He went home and his family broke the sad news to him in person.

Making grass mats



The family together

CHARGE SYNDROME:

Dual sensory impairment, Cognitive development and anxiety



Christine Tap

Charlotte Reau, Corinne Blouin and Christine Tap are all psychologists working in France. Christine is also Headteacher of CESSA, a school for deafblind children. This is the second article of a series of three which discuss methodology, cognitive development and the first clinical observations about anxiety. This is the second article and focusses on the first cognitive results.

The first cognitive results

In relation to our work on learning strategies we can see that the children

- have better competencies in practical tasks. They learn better when they can handle and have a concrete experience
- use a lot observation and imitation for learning and adapting to situations
- find processes of abstraction much more difficult (including a boy who reached the PIAGET Stage – formal intelligence). They have difficulties with mental representations of things and also with imagination
- could be observed that once a pattern is build up through observation, it is stable in time

- have difficulties with mental flexibility. So it is important to provide them with many models of action, that can be developed and enriched, which facilitates mental flexibility
- often use tactile information to supplement their visual perception. The tactile modality seems to facilitate attention and integration of information (e.g. to have a tactile contact with the child brings back his attention, tactile sign language can help the child to process information). Their hands seem sometimes to compensate for their eyes, that is why they need and love to manipulate. However, we suspect difficulties of bi-manual co-ordination with, for

some of them, the possible presence of disorders in the treatment of tactile information. Many of them use equally both hands or are left-handed

- appreciate one to one relationships
- show a craving for learning situations and for graphic supports (drawings, pictograms, writing)
- in spite of their visual, auditory and vestibular difficulties, they seem to have a good spatial orientation. All of them systematically explore new places and memorize them very well
- have difficulties with anticipating and planning actions or tasks. Facing a new task either they begin acting quickly (regardless of the instructions) or they keep getting stuck
- have difficulties in selecting relevant information relative to the requested task
- have difficulty memorizing complex information. Processing too much information create difficulties and lack of organisation (whatever

“... it is important to provide children with many models of action, that can be developed and enriched, which facilitates mental flexibility”



the cognitive level). This is especially true for visual information.

Therefore difficulties concerning executive functions will need to be explored more deeply.

In spite of these difficulties, they are children full of energy, always in search for human relations and learning? They are "all except lazy" according to David Brown

The first findings emerging from the grids about body security

What do we mean by body security?

All children try to ensure their own body security. What do we mean by "body

security?" It refers to a child developing a stabilized body position, preventing falling, drawing on more kinaesthetic information to locate the body in space. Once, a position is found and adopted, the child becomes more open to the human interaction and becomes more attentive to the task. These attitudes can be for example:

- chest supported on the table for reading;
- leaning on a wall carrying out a task (e.g: washing) or for communicating
- to squeeze oneself between the chair and the table for writing,
- to cross or twist the legs to observe a situation...

What have we learned so far about the place of anxiety?

- 1 The absence of the vestibular sense means no body security; causing distress and an agonising search for security.
- 2 Disturbance in the process of attachment of early childhood means difficulties in building one's own identity related to the consciousness of these difficulties.
- 3 Too little experience of peer interaction reinforces the difficulties of identification
- 4 Their sensory impairment requires from them a permanent attention and thus a constant tension.

The 3rd article will present the first results concerning the clinical observation.

And what is the impact of this acronym... CHARGE?

Some thoughts from Christine Tap.

We can see all the weight of the name of this syndrome: the syndrome C.H.A.R.G.E (pronounced and not spelled). It is composed of an association of letters which forms a word, the word "charge". We think that this label can have consequences and repercussions on the identity evolution of these children.

We have read, in a number of texts and scientific papers, the uses of this word (we can find in our language:) "the charge children ", "the charge" that can evoke a sense of a burden, a responsibility, guilt. In the same way, the French sign language label for this syndrome also represents a burden on the shoulder.

The association of these letters, in this order, has the potential, we

believe, to deeply modify our mental and psychological representations of these persons. This word, indicating a condition, and becoming its name, influences the representation that these people have of their body, of their body image. We believe it is joining this condition to their identity. More than labelling a condition, this word functions as a stigma.

We would like to ask colleagues using this acronym in different languages to tell us how it used in their country (English, Dutch, Spanish, German, Italian, Swedish...) and any comments on our thoughts on this subject.

Christine Tap
CESSA

Two great dates for deafblind people in Nepal!

Lone Poggioni keeps us up to date on the developments in Nepal

The 24th of October 2005 was a greatest day for deafblind children in Nepal! The Society of Deafblind Parents, which is a parents' organisation for deafblind children in Nepal, was finally official recognized by the Nepalese Government after nearly two years hard work!

The very first task for the new organisation was to hold a general assembly, which took place the 17th of November with plenty of positive outcomes.

- Mrs. Meena was elected as the president and Mrs. Sumitra as the treasurer.
- The by-laws of the Society of Deafblind Parents were elaborated and approved.
- The budget 2005/2006 was worked out, and an account in the Himalayan Bank was opened.
- The Statement of collaboration between The Danish Parents Organisation and the Society of Deafblind Parents made by Lone Poggioni was accepted and signed.
- Lone asked the parents to start preparing a workshop for parents and professionals in the beginning of 2007 with the object of evaluating the early running of the Deafblind Unit.

The President of the Society of Deafblind Parents will



work from her home initially but it is a future intention to rent a small office in the middle of Kathmandu. There may be possibility to share an office with a similar group. In a country like Nepal it is not easy to spread the news to parents of deafblind children about the new parent's organisation. The proposal from the parents was to use the local radio,

The President Mrs. Meena and the Treasurer Mrs. Sumitra



put announcements in local newspapers, and generally keep talking to everyone and ask them to spread the word trying to talk to neighbours! IT was agreed that the Society should join the National Federation of the Disabled-Nepal and the Social Welfare Council.

Before the President Mrs. Meena formally closed the meeting she thanked everybody for the wonderful support regarding starting the Deafblind Unit and in organising the general assembly.

The 24th of November 2005 the Nepalese Ministry of Education and Sport declared the first Deafblind Unit in Kathmandu to be opened by giving light to at lamp according to the local customs.

But before that wonderful day Inger Rødbroe and Bente Ramsing, Deafblindcenter in Aalborg, Denmark and Lone Poggioni, The Danish Parents Organisation had some very busy days!

The Model Project

After giving workshops to the parents of deafblind children in Kathmandu in November 2004 and seminars to the professionals the Danish team were ready to give support to start a Model Project for deafblind children in Kathmandu.

DSI/Danida, Denmark



The Minister and Inger Rødbroe at the Deafblind Unit



Lighting the lamp



Time for lunch

agreed to the financial support for this Project.

Why a Model Project?

Because among others:

- there is a lack of focus on the specific disability deafblindness and the absence of an overall education program for deafblind children in Nepal.
- the project is unique because of its integrated solutions contributing to a new area of rare and unnoticed disability groups.
- the Parents Society should gradually be able to develop into a strong, responsible, respected and competent association; thereby it may serve as a model for other disability groups.
- the project may function as a "knowledge bank" for other – especially – smaller disability groups by obtaining knowledge, experience and courage to undertake similar initiatives.
- the political authorities can get experience of this innovative project to ensure its financial security under Nepalese law after the withdrawal of the Danish team.

Our main objectives were to:

- support the start of a school unit with boarding facilities for deafblind children in Kathmandu.
- train the staff in order to enable them to teach the deafblind children until our next visit.
- enrol the first deaf blind children in the school.
- undertake formal arrangements to secure the Parents Society and the School.

Getting the Deafblind Unit up and running!

Mrs. Indira Shrestha, the director of the Deafblind Unit, advertised in the local Kathmandu newspaper for two teachers, three assistants, two fieldworkers and two housemothers.

The day after the Danish Team arrived we went to visit the Deafblind Unit. It seemed already very settled with a large classroom, two dormitories – one for girls and one for boys – and a bathroom with 3 toilets and 2 showers. We were really impressed to see what Mrs. Indira Shrestha had carried out in such a very short time.

Inger and Bente started at once on the training program for the new staff. Among others there were taught about:

- the characteristics of deafblindness and types of deafblindness
 - assessment and communication with congenital deafblind persons
 - mobility, how to teach daily living skills
 - schedule planning for deafblind students and individual planning
- Simulation exercises were held for the staff.

Finally we had a constructive talk to the two carpenters on the classroom furniture. He promised to finish his work before the official opening.

At the official ceremony





Activities



Staff training!



Communication!



The staff, Bente Ramsing and Inger Rødbroe

Opening of the Deafblind Unit

The carpenter had kept his promise. Two days before the official opening of the Deafblind Unit the furniture was delivered. It was all there, even the tables and the chairs. The tailor had managed to make an object-holder for each of the children – in different colours. It gave us the opportunity to arrange everything before the official opening.

The bags which we had brought from Denmark with items for assessing vision and hearing and all the music instruments bought in Kathmandu were locked into the cupboard with a key. Toys for playing, blankets for sitting on the floor, and kitchen utensils were put on the open cupboard for the children to learn to fetch things themselves.

All the deafblind children were nicely dressed in their new school uniforms. They all had shoes on their feet and they behaved very well during the opening ceremony.

The director, Mrs. Indira Shrestha, was the first one to speak. She thanked everybody for coming and gave – of course – a special thanks to the Ministry. Then there were several other speeches from the invited personalities. On behalf of the Danish team Inger Rødbroe offered her warmest congratulations to the Ministry of Education in Nepal and highlighted the huge step forward that Nepal had taken in opening the School and recognising the Parents Association. She

praised the siting of school with deaf children and emphasised the uniqueness of deafblindness and the specialist support the children will require to grow and learn. She described the hard work that would be ahead but reiterated that every school and service around the world had started like this! She said, "If you can teach a deafblind child to communicate, then you can teach any child to communicate!"

After the official opening the minister and all distinguished guests visited the Deafblind Unit to see how this new school was furnished.

The Future

The Danish Team has planned to go to Kathmandu late this year, with the following objectives:

- to enrol two more deafblind children, so the first class will have 6 children.
- to continue the staff training
- to help to the parents organisation for expand the Society of Deafblind Parents

Finally we will start working to get deafblindness recognized as a special disability and separate category in the national classification identification process.



Proyecto Aventura

Deafblind people in Bogota sign up for a big adventure!

Enrique King tells us more...

With the enthusiasm that has always characterized the activities Colombian Association of Deafblind People, SURCOE, volunteers and deafblind people arrived one by one to accept the challenge, some to prepare for and some to live, in the Simón Bolívar Park. This would be our first Great Adventure, as we are calling the new project supported by Sense International (Latin America).

On this particular day the sun shone more brightly than is customary in Bogotá, maybe in order to welcome this adventure that seeks to unite two shores that have been separated for quite some time now: Deafblind people and the society they are part of! Talking about the social inclusion of deafblind people looked far away and sounded strange to many, but when we accepted the challenge of launching ourselves into Adventure-In, we began to see and hear it with greater clarity.

In this first meeting, among games, laughter, and surprises, we presented the project to the members of the Colombian Association of Deafblind People. The project was presented through an activity that has the deafblind people search for a surprise



Bowling!

packet that was hidden between the trees of the park. The packet contained eye-catching hats with the project logo and from there, the only thing left was to start the adventure.

But in reality, what is Aventura-IN? Well, it's a new project, which, although at first it sounds strange, initiates inclusion with the intention of involving deafblind people into the everyday world through adventures. The entire project focuses on answering this question: What would deafblind people do at these ages in their life if they weren't deafblind?

It was then that, with the participation of members of SURCOE and the enthusiastic contribution of a group of committed volunteers, the ideas started flowing.

Making a high score..

After the beginning The Great Adventure, the challenge was to include ourselves like any other in a fascinating afternoon of bowling. Because it would be our first activity in the project, it was important for everything to go well. With the group of young people from SURCOE the secret was to arrive, and be with everyone else, live like them and enjoy a



Walking in the countryside, meeting horses

different type of afternoon. It was particularly resonant for everyone to discover how barriers could be broken and how strange it was for some to see how bowling instructions could be given, by using signs, touches, amplified sound or writing in the palm of the hand. But as the activity progressed it became more and more natural for everyone. The final scores: Nubia who is profoundly deaf with Usher syndrome knocked down 85 pins, Andres who is completely deafblind knocked down 77, Javier with 80, and the others with scores of 59, 49, and 19. Although Isaac only knocked down 9, his happiness far surpassed that of all the others.

Enjoying the countryside

For our second adventure with the group of older members we decided to

go for a walk through the savannah, which is the flat part of the region that Bogota is located in. That day, as is so common with the deafblind people, there was much enthusiasm. A light shower fell on us during the trip as if announcing God's good will. In the company of family, friends, and volunteers, we began an interesting walk in complete contact with the natural world. Sandra, who uses a cane to support her when she moves around, walked with everyone, enjoyed each smell, each sensation of contact with the flowers, the horses, the fresh air of the country side and the pleasant company of all her new friends.

A reminder of the adventure..

At the end of each activity, those that participated received a unique pin that

was proudly placed on their hat so that they would remember the adventure they lived. The collection of pins encourages the group to include themselves in more of these challenges. Our goal continues. Our next expedition will be with the youngest group, the children. We have planned an afternoon in the mall with everything a child could hope for; games, arcades, ice cream, and the most important, the chance to share and participate without inhibitions.

Lots more planned..

There is still much left for us to explore, and great ideas are still awaiting us. For recreation, we have, among other things, movies, dances, and the theatre. Soon, we hope to develop programs that can be open to society. We are planning groups of dances, theatre, mimes, handcrafts, culinary arts, and much more. With the project, we will make visits to libraries, museums, fairs, factories, conferences, and workshops. Also, we haven't left out sports activities like swimming, cycling, chess, board games, and even extreme sports. They have already made their first contacts with climbing, canoeing, and rafting.

Adventure encourages and stimulates us, but what most urges us to participate in adventures with deafblind people is the indescribable excitement that we see in everyone's face when we feel that, together, we are approaching this great shore that seemed so far away but now looks reachable.

The Prain Report on Deafblindness services

The Australian DeafBlind Council (ADBC), our peak policy and advocacy organization has spent much of 2004-5 on the dominant issue of the Commonwealth Government funded report on the needs of and services for Australians who are Deafblind. Research was undertaken by consultant Meredith Prain. The report has since become known as the Prain Report,

From receipt of funding to undertake the research, to lodgment of the report with the federal Government's Department of Commonwealth-State Relations, Disability and Carers Branch, the project took just over 12 months to complete.

The final result was due to an enormous effort and a lot of hard work by Meredith Prain with the support of her Steering Committee (Di Hartman, Pat Ellis, Celestine Hare and ADBC Executive Officer John Finch), and overview by the Reference Group, comprising all ADBC Committee Members. This meant that all States, with the exception of Tasmania, had a representative involved in the process. The Australian Capital Territory (ACT) and Northern Territory also lacked representation in the process. All States and Territories were approached for information.

The outcome of all this hard work has been a report, including appendices in excess of 120 pages, with 14 recommendations. The document provides a

significant review of the needs of people with Deafblindness in Australia.

The report currently awaits presentation to the Minister and, hopefully after this, will be available for distribution. It is planned to include a summary of the report in a future issue of ADBC Beacon.

Once the report has been distributed, the Committee plans to follow up its recommendations vigorously.

Research on deafblind TTY use in Australia

**From: Garry Croker
Manager, NRS Tender
Secretariat
Telecommunications
Competition and Consumer
Branch, Department
of Communications,
Information Technology
and the Arts**

A teletypewriter (TTY), as will be well known to many DbI Review readers, is a device that enables people who are deaf, hearing and/or speech impaired to communicate with anyone in the wider telephone network. In 2003, a review of TTY technology and its use in Australia was carried out by Network Strategies, a large telecommunications consultancy company. The review subsequently recommended that further research should be conducted to complete an accurate profile of TTY users and usage patterns in Australia, including residential and organisational users. A further study investigated the geo-demographic characteristics of TTY users, user preferences,

usage patterns and reasons for TTY use, as well as attitudes towards, and satisfaction with TTYs versus other technologies.

Research design

The research design had three main components.

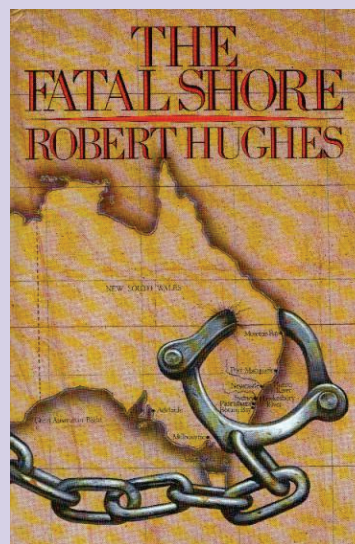
First, a mail survey was distributed to customers of Telstra's Disability Equipment Program (DEP). Telstra is an Australian telecommunications company that holds a predominant position in telephone-related services. An incentive was offered to encourage participation. A 'helpline' was established during this period and a follow-up letter was sent to maximise the response rate. The fieldwork period was from 12 November to 21 December, 2004. A total of 911 questionnaires were returned, giving a response rate of 41.4%.

Second, a separate qualitative research exercise was conducted

Australia



**Mike Steer
tells us
what's new
on the 'FATAL
SHORE'***



*The term 'Fatal Shore' is borrowed from the title of Robert Hughes' (1987) history of the painful emergence of Australia from prison camp to open society. It is used here as a term of endearment!!

Australia (continued)

with Deafblind TTY users (via interpreters) to explore the needs of these users. This included six in-depth interviews with Deafblind people from Sydney, Melbourne and regional Victoria and two interviews with community representatives.

The third component involved in-depth interviews with organisational TTY users to understand TTY use in that context. Nine interviews were conducted across a variety of private and public sector organisations.

TTY users

Based on comparison with the incidence in the Canadian population (0.064%), the Australian TTY user population was estimated at 12,800. The TTY user sample was comprised primarily of people residing in capital cities in the eastern states. There was slightly higher female representation than male and a reasonable spread of age groups. With regard to education, 13% had attended university and 28% had attended TAFE, college or some other tertiary institution. Over a third of the sample was in the labour force. Most respondents were from low income households. Almost two thirds were deaf (or Deaf) with another third having hearing difficulties, although just over half were comfortable using speech to some extent. Three quarters had English as a first language, followed by 18% for Auslan.

TTY use in Australia

Respondents had been using TTYs in general for an average of 9.4 years. The most common TTY models were the Uniphone 1150 and Superprint 4425. The majority of the sample had only one TTY in their household. Overall, 94% had access to a TTY in their home, and 11% had access elsewhere (e.g. work, or community centre). Half the sample had access to mobile phones, and this was relatively high among people aged between 20-29 years. Text to Voice and Voice Carry Over were the most common ways people had used the National Relay Service.

Across the sample, TTYs were not used very frequently. The percentage of TTY users who were using SMS on a daily basis was double that for either TTY to TTY calls or calls via the NRS. Email use was also relatively frequent. However, the results were more comparable when looking at use per week. The average number of TTY calls made in a given week was 4.7. SMS and email were the forms of communication most frequently used outside the home. Respondents perceived their use of email, SMS and (to a lesser extent) the NRS to have increased over the past two years, yet the net change in TTY to TTY use seemed to be small.

TTY to TTY calls were primarily used for calling Deaf or hearing impaired family and friends, whereas NRS calls were typically used for calling hearing people (including family, friends and organisations). SMS

and instant messaging were generally used to contact friends and family, rather than organisations, yet email was commonly used for the latter purpose as well.

Various questions in the survey assessed people's attitudes towards TTYs. Overall, the key perceived advantages of TTYs were that they offered personal, real-time communication that was reasonably easy and inexpensive to use and that, through the NRS, TTYs could connect people who were Deaf or had hearing or speech difficulties with the hearing community, including organisations. This gave TTY users a sense of independence. The main weaknesses of TTY were perceived to be technical malfunctions (e.g. breakdowns or scrambled text), the fact that calls took longer, and a lack of familiarity (and patience) with TTYs and the NRS among the general community (especially organisations). Overall, 84% of respondents were satisfied with TTYs. TTYs were still considered by many to be essential (especially for emergency situations), even if only used occasionally.

Awareness and use of public TTY payphones was very low, with many people relying on a hearing person or SMS in order to contact people when outside the home. The main issues with public TTY payphones included low awareness, both that they existed and of their locations, as well as problems or concerns regarding how they function.

The evidence suggests that SMS and email have relatively high popularity among TTY users, which is similar to their increasing popularity in the general population over recent years. The reasons for this, as well as evaluations of a range of other technologies, are discussed in detail in the report. Participant preferences indicate that TTY, SMS and email are currently the most popular options among this sample, with videophone technology seen as becoming more relevant and appealing in the future (particularly once issues regarding cost, picture quality and availability are addressed).

TTY use in the Deafblind community

Many attitudes held by deafblind participants regarding technologies were similar to those of the overall TTY survey sample. Deafblind people with only partial vision loss were able to use SMS and tended to prefer this over email. Yet those with total vision loss, who relied on Braille communication, lacked a portable communication solution for outside the home. Therefore, the latter group tended to rely more heavily on email. The perceived strengths and weaknesses of various alternative technologies are detailed further in the report.

TTY use in organisations

Based on the process of arranging the nine case studies, it would seem that the use of TTY technology in

organisations that deal with the public is inconsistent. Many organisations have a TTY number listed in the TTY Directory but do not have the machine connected or have no organisational capability to handle incoming TTY calls. Those that can locate and use their equipment typically have the same TTY machine that was originally installed five to ten years ago. Practices vary. Some organisations have a single TTY machine, with no one trained in its use. Others have several machines and/or several trained users. Generally, the more the organisation aspires to inclusivity and equality of access, the greater the measures in place to make use of TTY as a communication channel. Organisations with a particular interest in the Deaf and hearing impaired communities tended to have effective regimes in place, as did the Commonwealth agency and a university that were included in the research. Other organisations, while having taken the step of acquiring a TTY machine, lacked either the resources or the call volume to warrant supporting a dedicated, trained operator.

From: www.dcita.gov.au/.../reports/report_on_teletypewriter_tty_use_in_australia_2005.

Research on the Commonwealth Disability Strategy

Source: ACROD News Update. (ACROD is Australia's national industry association for Disability).

Commissioned by Australia's Federal Department of Family and Community Services (FaCS), Erebus International is currently conducting an evaluation of the Commonwealth Disability Strategy (CDS). The CDS impacts on the employment prospects of many Australians who are Deafblind. There was a call for submissions to the review during August last.

Introduced in 1994, the CDS provided a ten-year planning framework to assist Australian Government agencies to meet their obligations under the Commonwealth of Australia's Disability Discrimination Act 1992. The CDS is meant to remove barriers that prevent people with disabilities from having equal access to Government policies, programs, services, information and employment. In 1999 there was a mid-term evaluation of the CDS and a revised version was released in 2000. All Australian Government organisations are obliged to incorporate the objectives of the CDS into their strategic and business plans.

Few would disagree with the CDS's principles of equity, inclusion, participation, access and accountability. But, in a number of respects, the Strategy has been ineffective. The most glaring indicator of this is that the employment rate of people with disabilities by the Australian Government has declined significantly over the past decade: from 5.8% to 3.8%. Moreover, consultation processes that don't explicitly relate to disability policy,

Australia (continued)

information strategies and generic services are often not inclusive of people with disabilities.

Why has the Strategy not been more effective? The key problem, according to ACROD, is its marginal status in the business life of most Australian Government agencies. There is a lack of 'shared ownership' of the CDS across government. Most would view it as the responsibility of one branch within FaCS; and many agencies would simply not be aware of the range of actions available to them to make their programs, policies and practices more inclusive. Advice and support are available to help them be more inclusive, but most don't seek it. For example, according to the Australian Public Service Commission, only 21 out of 87 Commonwealth agencies are "working with organisations that specialise in placing people with a disability in employment". In addition, there are no obvious penalties for agencies that perform poorly in relation to the Strategy or rewards for those that perform well.

To be more effective the CDS needs more leverage and a higher profile. Locating responsibility for it in a central agency (Prime Minister and Cabinet)

would assist. Penalties and rewards for government agencies should be attached to the Strategy, with clear measures of success and failure developed. Agencies need more education about how to include people with disabilities in consultation processes, in employment and in the services they offer. Inclusion doesn't work well if it's approached grudgingly, as a matter of compliance. Thus, effort needs to be put into persuading agencies of the value and importance of involving people with disabilities in their core business.

Good news for crow eaters

(Ozzie nickname for South Australians!)

The South Australian Government is making it easier for people with disabilities to use public transport. It intends to spend A\$3.52 million over four years to change its current Transport Subsidy Scheme (SATSS) by significantly expanding eligibility

And by introducing a new Plus One companion card for travel on public transport.

The Plus One companion card scheme will mean free public transport for someone who is travelling with a person with a disability who

is unable to use transport on his/her own.

SATSS eligibility has been expanded from physical disability to include sensory impairment (e.g. vision), and cognitive and intellectual disabilities which result in an individual's permanent inability to use public transport. The scheme commenced on Friday 1 July 2005.

National Conference on Social Participation planned for 2006

ACROD, Australia's national industry association for Disability, will hold an inaugural National Conference on Social Participation in September 2006 in Adelaide. ACROD SA will host the conference, with ACROD's Conference Management Unit (located at National Office) responsible for its administration.

The National Conference on Social Participation is one of several specialist conferences to replace the ACROD National Convention. The National Accommodation and Community Support Conference was held in Melbourne last year, and the National Ageing and Disability Conference was held in July 2005 in Hobart, Tasmania.

Australia Queensland

Education Queensland's Deafblind/Multi-Sensory Impaired Web pages and the Tactile Sign Dictionary

Sandy Joint, the Statewide Education Advisor for Deafblind People in Queensland, Australia has been in touch with a really useful web address. It takes you to the EQ pages and the tactile sign dictionary that has been requested by many of you.

Here's the address and we will link from the Dbl website as well.

<http://www.learningplace.com.au/en/dssulc/dbmsi>

Great news – recognition of Deafblindness

Earlier this year Ricard Lopez was able to report some very exciting news about the status of deafblindness in Spain. After tireless lobbying Ricard has been able to announce to EdbN members that the government of Spain has now recognised deafblindness as a specific disability.

Ricard has become a very skilled campaigner using his skills and knowledge and encouraging others to do the same to further the cause of deafblind children and adults. He was able to use the European Union

declaration (01/2004) to help make his case and convinced the Socialist group members of Congress to take the issue forward. They are now having many meetings with government and establishing collaborative relationships in order to modify the present law relating to disability, dependency, education and health. This means real change is on the way!

He tells us that across the country families are pressing for change and this work is continuing in both Catalan and Aragon parliaments.

The latest news is they are lobbying the Spanish

parliament in relation to the new sign language law and the Catalan parliament for recognition. Ricard has been asked to write a proposal to change the old laws.

In another area, they have obtained the political agreement that in 2007 the state budget includes two specific residences: one in Seville and another one in Barcelona.

EDbN members have been delighted to hear of Ricard's success and are keen to emulate it!

Warmest congratulations Ricard and your fellow campaigners!

Spain



Ricard Lopez

What's new in Romania?

A new service for deafblind children and young people opened in Cluj-Napoca, Romania, last year in November. The Consultancy Centre on Deafblindness runs its activities at the Department of Special Education, Faculty of Psychology and Educational Sciences at the Babes-Bolyai University. The mission of the centre is to provide support for the families of deafblind children. The Centre also functions as a toy library, with a rich variety of toys, books, musical instruments and other objects that the parents can borrow for their children. It is a place where parents can meet and share information and experiences. It is also an environment that encourages opportunities for play and interaction for the group of deafblind teenagers that also use the centre. Another

objective is to do functional assessments of the child's potential in different areas of development and to develop Individualized Intervention Plans that are given to the child's intervener and parents, but also educational authorities if needed. The activities are developed and carried out by volunteers: Andrea Hathazi, Oana Farcas, Olimpia Luca, but also students from the faculty.

Another big and unique event in Romania was the course of national trainers in the domain of MSI/ Deafblindness. Eleven special education teachers, who were selected after the in-service training course held last year, in 2005, became national trainers after studying for 160 hours. The course was developed through a partnership between The Ministry of Education and

Research, The Department of Special Education, Babes-Bolyai University in Cluj. The course benefited from the theoretical and practical experience and knowledge of Dr Stuart Aitken, from Scotland but also specialists from Romania. The course covered subjects covering a wide area including alternative and augmentative communication, hand on hand communication, attachment, as well teaching strategies and competencies.

Romania has now a team of national trainers who will run courses in the future, but also give consultancy for teachers from different parts of the country, who work with MSI or deafblind children. It was the final stage of a project for in-service training financed by CfBT; a UK based trust that has supported work in Romania for many years.

Romania



Andrea Hathazi keeps us up to date

Scotland

Graeme
Thomson
reports

Mark Beattie collects major award

In March, Mark Beattie, who uses Sense Scotland's Family Resource Centre, celebrated two years worth of hard work in collecting his Bronze Duke of Edinburgh Award. Mark, who is 18, celebrated in style wearing a full kilt outfit and collecting the award from the Award's officer for Glasgow, Garry Mcloud.

Mark's journey had begun in May 2004 when he embarked on a remarkable project that brought deafblind performers from five different European countries together to devise and perform a piece of mainstream theatre to the paying public. The play, "Voyager Princess", was a huge success and months of hard work in rehearsals paid off as Mark stole the show playing the role of the cabin boy. During this leg of the Duke of Edinburgh's Award, Mark travelled to Italy for a week-long workshop, made many new friends and honed

his performance skills.

Mark's talents were tested further during the "service" component of the Award. He teamed up with Sense Scotland music tutor David McClusky and joined 'Partick Beat' a drumming group who were to perform in Glasgow's West End Festival. Over a 3-month period Mark honed his natural flair for percussion and played a full part in a vibrant and exciting performance in front of thousands of spectators.

The final challenge standing between Mark and his Award was the 'physical stage'. Mark, working with Joe Gibson, Sense Scotland's Outdoor Education Tutor, decided on rock climbing and entered a world of ropes, harnesses and helmets which culminated in Mark's navigation of "Windy Hill" in Muirshiel country park. The climb lived up to its name with heavy rain and wind making for a treacherous expedition with Mark

showing great determination and stamina to reach the summit.

A film of Mark's journey through the award was shown at the event, prompting cheers and not a few tears from a large crowd of friends, school colleagues, Sense Scotland staff and family members including mum Elaine and sisters Charlene and Nicole.

Sense Scotland's Creative Arts Tutor Jon Reid, who introduced and facilitated Mark through the award said: "This is a fabulous achievement for Mark. This is the first time a member of Sense Scotland has won the Duke of Edinburgh's Award, Mark is a true pioneer."

Chief Executive Gillian Morbey praised Mark for his achievement and expressed her pride in the Sense Scotland staff adding that this could be the beginning of an "exciting relationship providing real opportunities for the young people we support across Scotland."

Pictured left
to right: Joe
Gibson, Mark
Beattie, Viv
Rogers and
Jon Reid



It was a privilege for the FUNDAL Educational Center of Guatemala to host the Meeting of parents of deafblind and multiple-challenged persons, that took place during September 2005.

This event gave us the wonderful chance to get together with old friends and welcome all the new parents that join this big family every year.

We started enjoying this event from the very moment we were appointed hosts. During the planning meetings all the parents undertook their tasks with great responsibility and enthusiasm. As a result of we achieved our common goal: to organize, and develop each and every activity successfully to include everyone's voice.

The event took place in the facilities of IRTRA – a recreational center located



near the Pacific Coast in the department of Retalhuleu. The place was chosen because of the comfortable location and the wonderful weather and sights, which made it the perfect place to share and learn.

From the welcoming party, where everybody was warmly received, to each and every one of the little details we felt embraced by

Central America, Mexico and the Caribbean Parents Meeting

A report from Diana Bonilla



Regional News

the comforting feeling of being part of this wonderful work. For the parents coming from Guatemala, Mexico, Honduras, El Salvador, Costa Rica, Panama, Dominican Republic and Bolivia this experience was very valuable. Meeting and sharing with other people who, though in different environments, live the same challenges as each other is great.

Our consultants – from Argentina, María Verónica Cajal and from Brazil, Susana de Araoz are both mothers and professionals. With their expertise they chose the material and shared their knowledge in a warm way in order to ease the road that every deafblind or multiply-challenged parent has to walk through. Along the way we had also the help of our very dear friends Steve Perrault and Graciela Ferioli from the Hilton Perkins program who are kind-hearted professionals that always surprise us with their fresh and timely lessons of life.

We are very grateful to each and every one of the institutions that sponsored and assisted us in the organization of this event that aims to make the dream



a reality: They are Hilton Perkins, Fundación Once América Latina, and Christoffelblindenmision. However, we also want to point out the strength of parents who foster their children's effort,

and that of the educational and supporting institutions which help them carry out their work, because only with this kind of teamwork is it possible to reach the goals that transform lives.



Peru

Maria
Graciela
Laynes
reports:

Peru Celebrates 10 years of success!

To celebrate this important landmark for the Helen Keller Association of Peru an international seminar was held on the theme "Ten Years of Breaking the Barriers of Darkness and Silence"

Hilton/Perkins supported

part of this seminar and we welcomed Steve Perreault, Maria Bove and Ayola Cuestas. CBM collaborated with the participation of Sonia Margarita Villacres and Sense International with the participation of Ximena Serpa and Beatriz Satizabal.

More than 200 participants at the seminar heard contributions from these guests, as well as the knowledge, experience and philosophy of our deafblind students, families, members and professionals.

In-Sight and Tactual Profile!

Two instruments now available in English language versions

Visio, Institute for the Education of the Visually Impaired and Blind in the Netherlands, is pleased to announce the publication in English of the two instruments: In-Sight and Tactual Profile

- **In-Sight:** a diagnostic instrument designed to further the development of visual functioning in partially sighted children (six to twelve years of age) with a normal learning capacity. In-Sight has been structured around twelve categories of visual functioning. These categories have been divided into items increasing in difficulty. The price of this instrument is €1,299.00, excl. 6% VAT and transport costs (incl. VAT €1,377.00).

- **Tactual Profile:** an observation instrument for charting the tactual functioning of severely visually impaired children (from birth to sixteen years old). The instrument has been described in broad terms as constituting a "structured observation". Recently, research was carried out and the instrument was found to be valid. The price of this instrument is €1,794.00, excl. 6% VAT and transport costs (incl. VAT €1,902.00).

Special brochures are available. If you are interested, please e-mail your contact information to:

in-zicht@visio.nu,
Attn Ms Els Vervaart.
tactielprofiel@visio.nu,
Attn Ms Anneke Blok.

We will contact you within five days following receipt of your message.



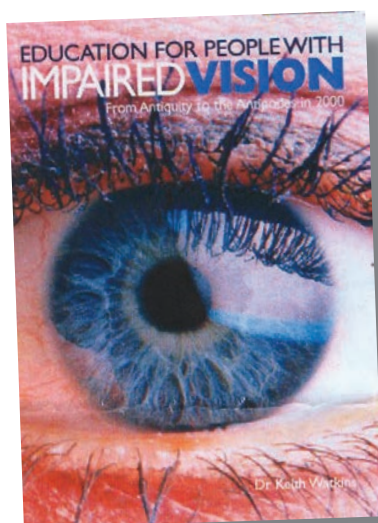
In-Sight



Tactual Profile

Education for People with Impaired Vision

From antiquity to the Antipodes 2000



Dr Keith Watkins

The story of Education for People with Visual Impairment traces the slow journey of such people – from the beggar at the city gates in the ancient world to the talking calculator, the post graduate degree and the computerised Braille invented in the last 30 years. To understand and appreciate the path taken by educators of people with impaired vision one must explore the historical links with Europe and America.

In describing the path trod by people with impaired vision, Keith Watkins presents a wealth of unique documents, reports and interviews. They provide a vivid picture of the birth and growth of special education for vision impaired students. This is history told in the social, economic and political climate of the times, making for absorbing reading.

ISBN: 064 645 1936

Contact keith.edie.watkins@bigpond.com to order the book!

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The Nordic Cultural Network

Lone Poggioni reports



In 2005 we had 4 courses with a total of 27 deafblind adults' participants from Norway, Denmark and

Sweden and 60 companions! They attended a "bronzing course" on the island of Gotland, a "nature sculpture course" at Johnsgaard Turistcenter, Sömdalen, Norway and two courses in "Communication in music" in Slettestrand, Denmark.

In 2006 the Nordic Cultural Network has planned the following courses:

- A "Bronzing Course" on the island Gotland, Sweden from 14 - 21 August - <http://www.gotland.se>
- A "Nature sculpture course" at Johnsgaard Turistcenter, Sömdalen, Norway from 01 - 07 September. - <http://www.johnsgard.no>
- One or two courses - if necessary - in "Communication in the music" in Slette-strand, Denmark from 23 - 28 October. - <http://www.slettestrand.dk>

The Siblings Network

At the moment of writing this update, we are preparing "Listen to me - 3", which will be held in Salou (Spain) from 1-8 October, 2006. During this family event, the Siblings Network is organising several siblings workshops. Here siblings of deafblind children can meet, exchange experiences and last but not least, have fun together!

The venue is situated close to the beach, so if we are lucky and the weather is good, we will be able to have some leisure activities on the beach as well.

It's important to mention that the information and discussions will be age appropriate as we want everyone to feel comfortable. Another important issue during the planning of the programme is

language. Most children attending will not speak English. We would like to encourage them to join anyway, as we are trying to divide the groups based on the language they speak.

Join us, it promises to be an interesting week!

For information on Listen to me 3 or the Siblings Network, please contact: siblingsnetwork@gmx.net

Sabine Kersten





Usher Study Group

Usher in Venezuela... some thoughts

Thanks to Maria-Luz Neri and the hard working staff in the SOCIEVEN office in Caracas we were able to hold a two and a half day workshop on all aspects of Usher syndrome, in March 2006, the first in Venezuela.

What struck me as I listened to the life stories from Rodolfo, Amarylis and Carolina who provided case studies in the Workshop was how familiar their stories seemed. Yes, the details of their lives were different but what they experienced with hearing loss, balance problems and the onset

of retinitis pigmentosa and then getting a diagnosis was common to people with Usher everywhere.

These common experiences could form the basis of core material about Usher syndrome.

This material could be put together in a basic pack of material which could be used by anyone who wanted to identify people with Usher in their own country or region. This core material could be translated and then tailored to the needs and culture of any country and used flexibly. This way it might be possible to identify people with



Usher even in isolated parts of the world and reach out to them and professionals who also need information.

If you think this is an idea we could build on please send your views to me.

mary.guest@sense.org.uk



Acquired Deafblindness Network (AdbN)

Ges Roulstone reports

The co-ordinating group of ADBN held their regular Spring meeting in Bergen on 1-2 April. At this meeting finishing touches were made to the programme for the **6th International Conference of ADBN**, to be held in **Groningen, Netherlands from 1-5 November 2006**. More details of this important and popular international event for everyone involved in the field of acquired deafblindness, appears on page 45.

The conference, entitled, "The Art of Communication – creating solutions on the individual, societal and organisational level in the world of Acquired Deafblindness", will feature plenary sessions from well-known speakers on Usher Syndrome, Technology and the political agenda. There will also be an exciting range of 16 workshops to choose from.

During the weekend the group also reviewed potential venues for the 7th conference in 2008, to be held in Bergen.



For more information and registration look at the **DbI website** or <http://adbn2006.visio.org>
email: deafblind@visio.nu or
telephone: +31 (0)55 580 06 96
fax: +31 (0)55 580 08 90.

MDVI Euronet

Rob Jones from the Royal Blind School, Edinburgh, reports

MDVI Euronet has continued on its mission to develop and share best practice in the education of children and young people with MDVI Euronet throughout 2005.

In July, the network completed its first European Union funded project which focused on the issues surrounding developing special schools as resource centres for mainstream providers. The final year's activities included the organisation of a series of dissemination seminars which were held in Scotland, Ireland, Sweden and the Czech Republic. The findings of the project can be found on MDVI Euronet's website at www.mdvi-euronet.org

The year also saw the network continue its development of the '5 Step Working Model' developed by Jon Magne Tellevik of the University of Oslo and Bengt Elmerskog from Tambartun Resource Centre. The aim of the project addresses one of the network's five stated priority areas which is staff training. The planning system under development aims to help teachers

plan a holistic approach centred on activities and participation in real life situations. For more details on this initiative, please visit the project's website at www.impact-mdvi.org

A number of MDVI Euronet members have also begun working on a school-based project called Look at Me Moving Forward! Six schools are participating in activities to challenge stereotypes which surround children and young people with a visual impairment or multiple disabilities and a visual impairment. However, the project also provides an excellent way of learning about other European cultures and building friendship between peoples. Information about this project can be found at www.sonokids.com/movingforward.

Finally, in November, members of the network met in Paris to develop a new project in another one of MDVI Euronet's priority areas namely Vocational Training. Attended by staff from 7 different countries, the group aims to establish a project which will

examine the concept of work for a young person with MDVI. The group agreed that 'going to work' is extremely important for self-esteem and social interaction, but there is a very real difference between work and employment.

Forthcoming Events

In the first quarter of 2006, information will be made available of a European In-service for teachers interested in the planning system developed by the ImPact MDVI programme. More information is at www.impact-mdvi.org.

Two seminars for professionals working with children and young people with MDVI are planned. The first of these addresses issues surrounding CVI and MDVI.

The second seminar will take place in autumn 2006 and is targeted at occupational therapists and physiotherapists.

For full details for both of these seminars, go to www.mdvi-euronet.org

Interpreters Development Network



Hello Everyone!
This network has only just started, so there isn't much news to tell about the

things we have done in the past.

We started at the 6th DbI Conference in Slovakia last summer and though we are new, we certainly do have plans for the future!

The Interpreter Network hopes to bring interpreters for the deafblind

and deafblind people themselves from various countries closer together to share information and materials. Deafblind people are very welcome because they can also share information and materials. We are aware that not all countries are equally advanced. For example, there is an issue about developing a system of paid interpreters and how to get this up and running. So we want to share ideas and answer questions together.

We will mainly communicate by email and if the possibility arises we would like to organise

a seminar about interpreting for deafblind people. Also we want to inform everyone about our group and what we are doing through our column in DbI Review. But we are also looking for members to express an interest and if you would like to keep informed through a e-mail list, please let me know you! Mail me at: mirjam.leusink@planet.nl

Kind regards,
Mirjam Leusink
Chairperson for ID Network

Communication Network

Communication with congenital deafblind persons – a collaboration to produce materials

Inger Rødbroe writes

The Deafblind Department of Viataal, in the Netherlands and the Nordic Staff Training Centre (representing the five Nordic countries) have worked together over many years and developed a lot of knowledge and understanding about the process of interaction and communication with persons with congenital deafblindness.

In the summer of 2004 Viataal and NUD decided to start to write up this work in order to share it more widely. The decision was taken to work on 4 booklets and illustrate the content of the booklets using video examples on a set of 4 DVD. The booklets and DVD can be used in train-the-trainer programmes for transmission of knowledge, in courses, and in the day-to-day-practice.

This project is based on the long term study of Dbl's Communication Network and for this project its members act as a review group. Inger Rødbroe from the Danish Resource Centre on Congenital Deafblindness is leading on the content and Annet Eikelboom from Viataal, is leading on the production. Since the summer of 2005 the Danish Resource Centre on Congenital Deafblindness has represented the Nordic part of the project. The entire project will finish in March 2008.

Products

Topics of the booklets and the DVD:

1. **Congenital deafblindness and the core principles of intervention**
Target date – June 2006
2. **Social interaction and contact**
Target date – June 2006
3. **Communication based on non-conventional "signs"**
Target date – June 2006
4. **Communication based on conventional "signs"**
Target date – June 2006

The target group of these booklets is professionals and parents who are working and supporting congenitally deafblind children and adults. Each booklet will contain general theoretical background information, deafblind specific information and examples that are written, linked and expanded in the DVD. The DVD will have subtitles when necessary for the viewer to follow the ongoing conversations.

Developing expertise among the involved consultants.

The Nordic and Dutch consultants are involved in collecting video examples and in the writing process of booklet 3 and 4. Later on they will be able to pass on the content of the developed booklets to colleagues, professionals and interested parents. They are the ambassadors for the project. Dates

for the training included in the project are not available yet.

Information about this project

Information about this project will be shared on Dbl website under the Communication Network. Websites of the participating institutions will get a translation of the text and a link to the DBI website. We are aiming at summer 2006 to have the information of this project ready to go!

Publication starts in Summer 2006 and continues...

Booklets 1 and 2 are ready now and layout and printing will be happen in June 2006. The DVD of Booklet 1 will be ready at the end of March and the DVD of Booklet 2 will be ready in June.

During a 3-day meeting in April 2005 at NUD, the participating consultants from the Nordic countries and the Netherlands developed the outline of Booklet 3. These consultants have started the writing process by working in international teams on the development of source texts that will form the base of the booklet. Booklet 3 and the DVD will be ready in June 2007. The writing process of the fourth booklet will be similar to the development of Booklet 3.

The writing process of Booklet 4 will start at a seminar at Vital, October 2006.

In autumn 2007 when the DBI World Conference will take place in Australia we intend to present the results of the project so far!

Employment Network

Seija Troyano shares some personal experiences with us

For eighteen years I have taken a great interest in what is happening within the field of employment for deafblind people and how the "labour" officers and professionals around us work out the problems that deafblind and other disabled people face while trying to find a job.

Far too often the comment is that there are so many people without work around us who aren't disabled that unemployment is a problem for everyone today. The comment like that is certainly not a key to solve the problem whatsoever!

When I started my work as a town councillor few years ago, I took a special interest to see through what are the modern tools are applied to unemployment and more accurately, what are the tools to employ disabled people professional education.

In June 2005 I decided personally to take part in a project that the Employment Office offered for those with professional education but a limited chance to work because of handicap or any illness. The person who runs the project is very friendly and has offered time to find out what is the situation for individuals but soon it will be launched more widely. The project also has responsibility to obtain results! This means that the person running the project is trying very hard. I told her once, kindly, that I have given myself permission to be critical and not to accept anything which I think is not for me. As an adult, we are not running after things we know are not for us. We also know what is realistic.

Now the latest phase of the project is a two-week special & intensive course for six individuals to train them how to look for a job!

As I write this, the first week is just over and another one ahead. There were two women with me on the course who I knew were very well educated – one of them is blind and one with poor sight. The second day of our "special course" ended with repetition of the things we already knew! I am really frustrated at the thought of where all that money goes which aim is to "help" us to find job!

The only reality we found was that we were able to give special feedback to the two women who run the course. These women were very nice and friendly which helped us to relax and joke in spite of the situation: each of us got a personal computer and we were asked to open it and go to the www-pages where we can find what the labour market offers openly... So... the blind lady could not use the computer at all without her personal aids, I could not use the www-pages because the pages were not meant for person with poor sight. So the course continued with us helping and encouraging the fourth lady who has "only" diabetes and a poor back. Her self esteem was not the best possible and she needed quite a lot of encouragement. We were very good at it! And we so very good that this woman sent off her application for a job as a general help on a bus that is meant for disabled and old people.

And here I am now – wondering what the next week will bring us when it comes! So many years and



here we are! Still!

The blind lady on our course has a High School degree and education that many sighted and hearing people could envy. She had – surprisingly – tried to get that very project job we are attending – without result. She knows and she understands the problems blind and deafblind face. She also understands which are the tools to help us have access to work. But as it goes, far too often, there are others around us who know better what we need and which way!

The only thing that keeps me going in this frustrating situation is to know that the Parliament has finally "woken up" to see what a positive and meaningful thing it is to employ disabled people. The Parliament itself recently employed learning disabled young woman to help in the kitchen duties. All the media noticed it – everything went very well and both the young lady and those MPs were delighted with the situation!

The show must go on – there is much to do for all of us to reach the top of the mountain we are heading to!

To join the network, contact:
seija.troyano@dnainternet.net



A D B N



6th European seminar of the Acquired Deafblindness Network
1 – 5 November 2006 in Groningen, The Netherlands

THE ART OF COMMUNICATION — CREATING SOLUTIONS ON THE INDIVIDUAL, SOCIETAL AND ORGANISATIONAL LEVEL IN THE WORLD OF ACQUIRED DEAFBLINDNESS

THEME

This seminar will continue on the 5th European seminar of the Acquired Deafblindness Network. We will be exploring creative solutions to improve the communication with all kinds of acquired deafblindness

As part of this process we will discuss communication solutions of deafblind people, what opportunities can be created and how we can turn possibilities into realities together.

CONFERENCE RESORT AND HOTEL

Meerwold, Laan Corpus den Hoorn 300, 9728 JT Groningen, The Netherlands
(www.meerwold.nl)

THE ACQUIRED DEAFBLINDNESS NETWORK

The Acquired Deafblindness Network aims to create and support people who are involved in the world of acquired deafblindness.

THE PROGRAMME

The Conference has put together an outstanding programme of presentations and workshops. Please consult the website for application forms or contact:

Linda Kerssies

Visio, Waldeck-Pyrmontstraat 31, 7315 JH Apeldoorn, The Netherlands

deafblind@visio.nu

JOIN US!

www.deafblindinternational.org

Change – the future looks brighter?

Lex Grandia reports from the United Nations

Although it may seem from time to time, that nothing is changing in this world: poverty, conflicts, isolation, there are changes on the way.

One of my main activities as President of the World Federation of the DeafBlind at the moment is my every day involvement in negotiations at the UN on the convention on the rights of persons with disabilities. This negotiation process started in 2001 and will probably finish in August 2006. Although the governments of the 191 UN member states make the final decisions, the international disability organisations, united in the international disability caucus, (Idc) are trying to influence the decision making. There is still a difference between the views and wishes of Idc and what the different governments, from their different cultural perspectives, can accept to have in the text of this convention. I hope to explain to you what is happening.

What is a convention?

A convention is an international legal document. It is a kind of legal contract

between the government of each country with every individual person with a disability. It covers all aspects of life. It contains legal rules; articles that describe the general principles and obligations of the public authorities towards every individual person with a disability.

Deafblindness is a disability, although not recognised in every country. Once the UN General Assembly has approved the convention and governments start to ratify, it will have influence on national legislation in each country. It is going to effect the position of deafblind persons, their families and professionals in the near future. The convention will also include the description of a monitoring system that will look at the implementation of the more than 40 articles in the text. That is even more important now the commission of human rights in Geneva is changing into a much more powerful Council of Human Rights.

Working on a legal binding document is very complicated and the biggest fear of Idc is that we exclude people with disabilities that we don't know about now – and in the future. I can only give a few examples here on how the process is going, but I will take the most important ones.

Legal Capacity

A very difficult issue is the concept of "legal capacity". Legal capacity means that every deafblind person is an equal person before and under the law. Every deafblind person should have individual autonomy (self-determination) concerning all aspects of life. Closely connected to this concept is respect for the integrity of the person. That implies that no inhuman and degrading treatment, no punishment, no exploitation or abuse is legitimate.

So far so good, but what happens, if I am congenitally deafblind and have difficulties in understanding or communicating? Or what happens if I am in a coma? In those and other cases I am not able to exercise my legal capacity.

Here we have an enormous conflict between many governments and the Idc and that needs to be solved before the end of August. This conflict has arisen because in many countries my legal capacity is taken away. Somebody else, a family member, an advocate or a professional is acting as my substitute, making decisions concerning me, without me.

This concept of substitute decision-making is unacceptable to Idc. Idc recognises the many situations where I am



Lex Grandia at the UN



Report from the United Nations

(temporarily or permanently) unable to exercise my legal capacity, but Idc prefers the concept of supportive decision-making. Decisions made on my behalf should support me and nobody else. Of course, there are situations that I can not be sure that somebody is making decisions that support me, especially when I don't understand what it is all about. It makes, however, every action on my behalf, that does not support me, illegal. It also gives the obligation to give me all information necessary to make my own decisions, in case I am able to exercise my legal capacity.

I am sorry to be a bit abstract here, but it is the legal basis of the whole convention. Let me give a more concrete example. I think it touches us all. In the description of modes of communication sign languages and tactile communication are involved so far. So, I will also get the right to express myself in my own way using modes of communication I prefer, but what about my education as a deafblind person? There

Some view!



is an enormous support for inclusive education among the governments and also in the Idc. The term: "special education" will not be used in this convention. There is an even bigger problem: we cannot agree on what the term "inclusive education" means. So a child may face the risk of losing the opportunity to get education together with deafblind peers in our own settings. A child would have to develop communication skills, learn Braille, explore my environment and develop my daily life activities with other senses, than ears and eyes without a specialist environment in which to begin. And what about mobility? The organisations of deaf, blind and deafblind people have been fighting to keep this right for children mentioned in the convention. It is still there in the latest draft, but very weak. I hope I will succeed in maintaining it.

There are many other

controversial issues including all forms of accessibility, health, rehabilitation, employment and the position of sheltered workshops, standard of living and social security. These all have an impact on poverty reduction respect for the home and the family, forced interventions and forced institutionalisation. These issues are not resolved yet and may also depend on what governments' priorities are for their resources. The aim, however, remains full inclusion of all persons with disabilities in society on an equal basis with others. I hope this convention will improve the quality of life for all deafblind people.

With Willian
Rowland

Lex with Kiki
Nordstrøm



DbI Asia conference



**2nd Asian Conference of DbI
Dhaka, Bangladesh
January 29-31, 2006
DbI & NFOWD**





14th Deafblind International World Conference

25th – 30th September 2007

“Dear members and friends of the Deafblind International community

It is with great pleasure and pride that I invite you to the State of Western Australia to attend the 14th Deafblind International World Conference in September 2007.

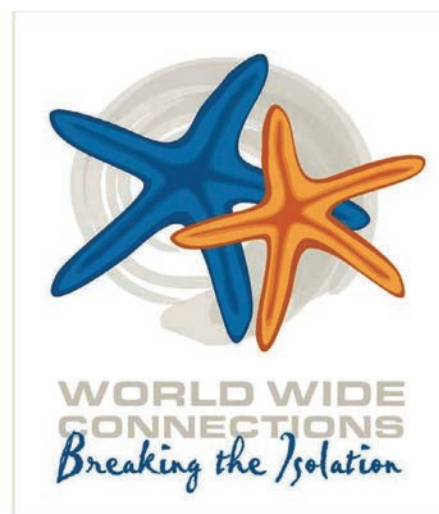
By attending the conference you will have a wonderful opportunity to exchange ideas and information on issues of mutual interest and work towards **“Breaking the Isolation”** and forming **“Worldwide Connections”** with others involved in the highly valued work that you do.



On behalf of all West Australians, I invite you to experience our hospitality, our vibrant city and our wonderful natural environment and to join us in Perth in September 2007, for a worthwhile conference and a wonderful visit.”

Alan Carpenter

Premier, Western Australia



Register online:

www.dbiconference2007.asn.au

Come to the 14th Deafblind International World Conference for a professionally stimulating, diverse and authoritative conference and see Perth, the capital of Western Australia, and one of Australia’s most stunningly beautiful cities. With pristine beaches, pleasant Mediterranean climate, clean environment and open relaxed lifestyle, Perth, Western Australia is the place to be in September 2007.

Come on – you have always wanted to see Australia!

EDbN

Bcn'06



Listen to me 3



The logo of "Listen to me 3" imitates the "castells" (human towers) because it needs the teamwork of many people. The same as each person with deafblindness does to join in.

EDbN European Family Event 2006 "Parent Power".

The 5th European Family Conference is being held in **Salou** (near Barcelona), Catalonia – Spain, in October 2006 from the 1st until the 6th. The previous family conferences were held in Slovakia, The Netherlands, Italy and Denmark. These events are called "Listen to me" so the Salou event will be called "**Listen to me 3**".

Barcelona (BCN) has a very important international airport (1½ hours drive) and there is a second international airport in Reus (**REU**), used by charter airlines, 15 minutes from Salou. There are various cheaper airlines.

Tarragona, (10 minutes drive from Salou) with many monuments from the Roman times is now a Unesco site, and is also close by.

Gaudí, Dalí, Picasso are some of the Catalan artists. Barcelona is an important tourist site. In Catalonia the beaches are splendid and there are a lot of tourist sites suitable for family holidays.

The conference will have specific activities organised by the EDbN for parents and for deafblind people, and for siblings organized by the Siblings network. The most important organizations are supporting the event:

- ✓ Hilton Perkins.
- ✓ Lega del Filo d'Oro.
- ✓ ONCE
- ✓ Sense.

Some of the meeting will be on the themes: Learning and teaching sexual education to Db people; The Cochlear Implant: what is it, what is the up-to-date situation; deafblind youngsters, planning their future; work integration of young people who are deafblind; Hereditary diseases of the retina, what is happening...

Several **tourist activities** have been organized. A guided day trip to Barcelona City will be the central activity. Every night there will be artistic activities for everybody, thanks to several Catalan folk groups. There will be a chance to visit **Port Aventura theme park** This is a place with shows and attractions for all the family close to the hotel.

Conference fee (Including accommodation, transport from/to the airport, the Barcelona visit, all meals and conference papers): 250 Euro per person, 325 Euro per person after May 15.

To **register** or to request **more information** on the Conference and be on the mailing list contact:

European Deafblind Network; Hotel d'Entitats de La Pau; Carrer Pere Vergés, 1 despatxh 10-2; 08020 Barcelona. Catalonia. Spain. Tel: +34 93305 4385; fax: +3493331 4220; sms: +34 678 712619; email: rlopez@sordoceguera.com



Narratives from everyday life...

"Experiences from people with deafblindness – a Nordic project" has recently been published by the Information Center for Acquired Deafblindness in Denmark. It is subtitled "Narratives of everyday life" and it focuses on the practical, emotional and social consequences of having a progressive hearing and visual disability.

Twenty people with Usher Syndrome have been at the heart of the project and they have contributed through interview and discussion annually for five years. The result of this thoughtful project is 6 booklets entitled:

- Theory and methods**
- Receiving a diagnosis**
- Getting support**
- Being active**



Getting an education and work Narratives from everyday life

Kirsten Jansbøl and Birgitte Ravn Olesen are the authors, but deafblind people and professional colleagues from Norway, Sweden, Iceland and Denmark have been

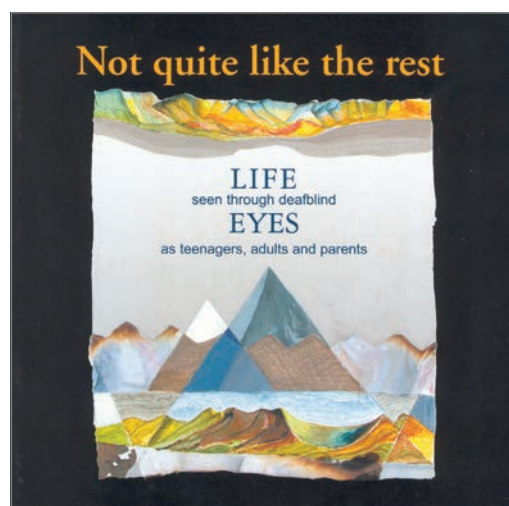
partners. More information is available from the Information Center for Acquired Deafblindness in Denmark. Their web address is: www.dbcent.dk

Do get in touch if you are interested in learning more.



Recognition reports a survey of deafblindness in the European Union to find out the actual situation in the member states of the recognition of deafblindness as a separate disability. Twenty-nine organisations across Europe contributed.

The report is available from EDbN, c/o Lucy Drescher, Sense, 11-13 Clifton Terrace, London N4 3SR website www.edbn.org



This video and booklet was produced by the Information Centre for Deafblindness in Denmark, to meet requests from many parts of the Danish community for more, and better information about deafblindness. Developed with a number of deafblind people this material could be used in very many ways to support understanding, inspire discussion and promote change.

Do get in touch to find out more at www.dbcent.dk
ISBN 87- 990212 -1-8



2011 World Conference

Dear friends,

Are you interested in hosting the 2011 Dbl World Conference?

It seems a long way away, but the next World Conference will be next year in Australia and at that conference the hosts of the 2011 conference will be announced. The process for making that decision starts now!

The World Conference is the major event in Dbl's programme. It takes place every four years and is the main opportunity for all those involved in Dbl to come together at the global level.

It has been decided that for the 2011 World Conference priority will be given to applications from outside Western Europe and North America. There was a World Conference in Argentina in 1995 and following that they have been held in Portugal, Canada and Australia. We do not want to go from 1995 to 2015 without being in a developing country. For that reason it has been decided that the 2011 conference really should be outside Western Europe and North America and this will be prioritised during the decision-making process.

For information about how to apply and for any other information you might require at this stage please contact Richard Hawkes, Secretary of Dbl at Richard.Hawkes@senseinternational.org.uk. In brief, expressions of interest must be with me by 31st October 2006. There will then be further discussions, followed by a deadline for full applications of 31st March 2007.

I look forward to hearing from you.

Very best wishes,

Richard

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The search for our next President begins!

Dear Dbl members,

I am pleased to announce that the Nominations Committee is established and we are starting to consider our tasks. I am the Chair and our willing volunteers are Bhushan Punani from India, Knut Johansen from Norway, Mike Collins from USA and Ricard Lopez from Catalonia/Spain.

We will be considering the President and two Vice President positions along with an overall vision for a Council that will work hard for us and take account of all our interests, regardless of where we live. Our job is to make

recommendations to the General Assembly that will take place at the world conference in Australia in 2007.

The Nominations Committee wants to consult as widely as possible. Please don't feel you have to have detailed knowledge of constitutions or sophisticated systems we really just want to hear from you! Over the next year we would like you to tell us about the people and issues you would like us to know about so we can get the job done successfully!

There will be other opportunities to contribute over the coming months

but in the meantime we welcome any thoughts – so please send us your views.

You can send your points to any of the members or to me as Chair

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Or write to:

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Secretariat News



Sumitra Mishra

Dbl Management Committee meeting took place on 28 January 2006 in Bangladesh prior to the Dbl Asia Conference.

Next Dbl Council meeting and Dbl Management Committee meeting is scheduled to coincide with the 12th ICEVI World Conference at Kuala Lumpur, Malaysia. If you want more details on these meetings, contact the Secretariat at: secretariat@deafblindinternational.org.

Dbl Asia Conference – Bangladesh, 29-31 January 2006

The Second Dbl Asia Conference with the theme "Deafblindness – Breaking Barriers in Asia" was held from 29 – 31 January 2006 in Dhaka, Bangladesh. More than 320 participants from 18 countries attended the conference. It was the first stand alone conference that Dbl has organised in Asia. It is therefore a fantastic achievement and an enormous success that there were so many people present. Full proceedings of the conference are available at: www.deafblindinternational.org/standard/dbi_proceedings.html.

The next major Dbl event coming up:

- The 14th Dbl World Conference will be held from 25-30 September 2007 at Burswood Resort in Perth, Western Australia. It is being organised by Senses Foundation. The Scientific Committee is meeting again in July 2006 in Malaysia.

Membership Update

All Dbl members are encouraged to renew your membership, if you have not done so already. Please quote your specially assigned membership number in all communications.

There are currently more than 650 individual members and 55 corporate members, from more than 80 different countries.

If you know of any organisation that may be interested to join Dbl as a corporate member, please pass on their details to the Secretariat now!

Dbl would like to express its appreciation for the continued support of the large and small corporate members. We strongly encourage individuals to join Dbl in order to contribute to and widen our global community in the field of deafblindness.

If you have any queries regarding the status of your membership, please do not hesitate to contact the Secretariat at: secretariat@deafblindinternational.org or post your query to:

Dbl Secretariat, Post Box No: 9601, Janakpuri, New Delhi – 110058, India.

Dbl Website

The Dbl website is available with updated information. Please visit the website and share your feedback with us.

We welcome new submissions to the website so if you would like to contribute or advertise an event or recent success, please send details to Eileen Boothroyd, Dbl Information Officer, at Eileen.Boothroyd@sense.org.uk.

The Dbl Secretariat

The Dbl Secretariat is always aiming to improve the service that we offer. We look forward to your suggestions, advice and support for providing a timely and effective service.

We hope that you received your copy of the previous issue of Dbl Review (issue 36). If you have not received your copy, please contact the Secretariat. We are also keen to update the information we have about you and your organisation, so kindly make sure you send your membership renewal forms with your latest contact details to the Secretariat.



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 two tiers of **Corporate Membership:**

Large Corporates:
Annual Fees between €3,000 and €5,000

Small Corporates:
Annual Fees between €300 and €1,500

Corporate Members can be nominated to sit on the Council.



DbI

DEAFBLIND INTERNATIONAL

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. | |
| <i>(Please include country and area codes)</i> | | |
| 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)

A. I would prefer to receive *DbI Review* in:

- ☐ English

B. 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 an annual membership fee of €30
☐ I wish to pay for 4 years' membership at the **discounted rate** of €100
☐ Please waive my membership fee as I am unable to pay it at present. Please contact me.

Corporate Membership

There are two tiers of Corporate Membership:

Large corporates

Annual fees between €3,000 and €5,000

Small corporates

Annual fees between €300 and €1,500

- ☐ We would like to join DbI as a Large/Small Corporate Member *(please delete as appropriate)*

We submit an annual fee of € _____

Corporate members are entitled to receive up to 25 copies of *DbI Review*. We would like- _____ copies in ☐ English ☐ Spanish *(delete as appropriate)*

Member Details:

| | |
|--|--------------|
| Organisation | |
| Representative | |
| Address (Line 1) | |
| Address (Line 2) | |
| Town/City | State/County |
| Zip/Post Code | Country |
| Tel: | |
| <i>(please include country & area codes)</i> | |
| Fax: | |
| <i>(please include country & area codes)</i> | |
| Email: | |

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. However, if it is really not possible for you to pay by bank transfer and you do have to pay by cheque or credit card, maybe you could do so for four years instead of just the one.

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: _____

Please note that credit card payments are made to Sense who then credit DbI.

C) Payment by cheque

If paying by cheque, please make cheques payable to 'Deafblind International' and send to the address given below. If paying by Eurocheque, please make out cheque in euros.

Please fax this whole page to 91-11-25618430 or return to:

The Secretariat, Deafblind International, Post Box No 9601, Janakpuri, New Delhi – 110058, INDIA.

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