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THE MAGAZINE
OF DEAFBLIND
INTERNATIONAL

● Number 31 • January – June 2003

Review



Working in partnership

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

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

The editor will be pleased to receive articles, news items, letters, notices of books and information on forthcoming events, such as conferences and courses, concerning deafblind children, young adults and older people. Photographs and drawings are welcome; they will be copied and returned.

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

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

Dbl Review is also available in Spanish or on disk. If you are interested in receiving your copy in either of these formats please contact:

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Cover: Henryk Kowalczyk creates the sculpture, 'Babel Tower'.

A message from the president

As I write this final message, (gulp, did I say *final*? I hope not.) it is all so very clear to me how quickly time has passed. This is now the twilight of my four-year Presidency, which was preceded by eight years as Vice President for Dbl. So a dozen years have passed since I first agreed to accept nomination as an honorary officer, during the Orebro Conference. It scarcely seems possible. It is in the same league as my children finishing graduate school and becoming married, setting out on their own careers as teachers or in economics. It is such milestones that remind us of our own changes and the mad pace that Father Time seems to maintain. When I first attended a Dbl world conference, in Hanover, Germany, I felt like one of the grandchildren in the field; I have to say that now I feel like one of the grandfathers!

It is not with regret, but with eager anticipation, that I will be moving into the role of "Immediate Past President". This means I still get to be intimately involved with the inner workings of Dbl but without all the responsibility of being in the lead decision-making role. I still come to the table, but I eat only what I want!

During the past four years we have witnessed many changes, both within Dbl and within the world as a whole. We have somehow survived the stepping down of a very strong leader in the person of Marjaana Suosalmi. To complicate matters, we have



also endured the retirement of the mainstay of our organization for the past decade in the person of our Secretary, Rodney Clark. Fortunately we have had other strong leaders come forward to assist our organization, persons new to the management of Dbl, such as Ton Visser, Emanuela Brahamsha, Richard Hawkes, Anny Koppen and Bernadette Kappen, along with a very able manager in the person of Emma Fisher. Thanks to their strong support and that of other veterans such as Malcolm Matthews, Eileen Boothroyd and William Green, we have weathered these changes quite successfully. Dbl has continued to grow, has found itself on firm financial footing, and remains focused on its original purposes, thanks to the hard work and dedication of these people. We all owe them a terrific expression of gratitude for their contributions during this period.

These recent years have not been the simplest with regard to the state of world affairs. War, terrorism and

health issues have had an incontrovertible effect on our work, and on the positive aspects of globalization within the human services realm. We have all experienced worry and anxiety caused by acts of violence and aggression, and some of us have been forced to cancel some very important work due to these forces. Likewise, the state of our world conference had remained in doubt until very recently due to SARS and its effects in Canada. When we selected Canada four years ago as our next site for a world meeting, we thought we were doing so in absolute confidence that it was secure and a safe bet for any such meeting. As said in some parts of my country, "Who

woulda thunk it?". No wonder we have gray hairs.

If there has been one lesson learned from the trying times within and outside of our organization, it is that we must keep our focus, and keep moving forward, with all the enthusiasm and energy that our work generates for us. We have seen the world change a lot for the better in the past decade, especially in our area of concern. Let us assure that deafblind education and services continue to improve even more so in the coming years.

Thanks to each of you for the support you have afforded me during these years. I look forward to our continued work together.

Michael T. Collins,
President, Dbl

EDITORIAL

"Working in partnership" is the theme running through the magazine this time and much of the focus is on celebrating the achievements of deafblind people and their friends, family and colleagues as they work together to make things happen!

For a long time now I have admired the work of the Nordic Culture Network for its ability to inspire, and make art that itself inspires! The Network has a major programme of events each year and we have a taste of this, the nature sculpture classes in Norway, reported this time. In Eastern Europe too, Polish artists have been working in partnership with deafblind people and their massive and monumental clay sculptures are featured in a fascinating article that

discusses personal spirituality and the power of the "can do" attitude of their Polish artist/partners.

"Communication partners" is the subject of Paul Hart's contribution and his article adds to current thinking in this important area.

We have our regular correspondence from all over the world and our very first article from Kazakhstan about progress of a new organisation and a proposal of a new Dbl Network – for siblings.

Again, thank you all for your support and we look forward to hearing from you – about your work, your family or your service! If you are fortunate enough to be going to Canada I look forward to seeing you there.

Eileen and Frances

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The role of a partner in communication episodes with a deafblind person

Paul is currently Principal Officer for Practice Development for Sense Scotland in Glasgow where he spends much of his time developing and delivering training courses, supporting the development of communication strategies with individuals and thinking about new ways of supporting people with multiple difficulties. In this paper Paul examines the notion of communication partners drawing on his own experience.

Rødbye and Souriau (2000) argue that deafblind children need ongoing intervention from communication partners if they are to develop communication competencies. This intervention should be based on the natural way all children learn to communicate and drawing on Vygotsky, they state that the partner's role is to discover and then support new emerging competencies, but never to train competencies that are not ready to emerge. Vygotsky also overshadows the notion of 'co-creative communication' (Nafstad and Rødbye, 1999) but they draw also on the concept of 'scaffolding' to describe the role of the partner and this then begins to suggest that the communication partner is the more competent.

This review explores the importance of viewing the development of deafblind children from a social constructivist perspective, but aims also to explore what this might suggest for relationships that exist between deafblind people and their communication partners. Vygotsky (1999) described the Zone of Proximal Development as the distance between the actual and potential developmental levels of children. This gap is bridged with the help of more competent others. Brownell and Carriger (1998) also suggest that social relationships are the contexts in which knowledge is formed. This is echoed by Meadows (1999) who considers cognitive abilities not to be 'internal and individualistic' but built up in interactions with the environment. All of this is relevant for deafblind



Paul Hart

children, particularly if we recall Macmurray's view that "the unit of personal existence is not the individual but two persons in personal relation". (Faulkner and Woodhead (1999)).

However, when we begin to consider Vygotsky's view that instruction from more competent others is a central feature of the learning process within the ZPD, a number of challenges are raised in relation to how deafblind people learn to communicate. Wood (1988) suggests learning is 'scaffolded'; Rogoff et al (1998) offer the term 'guided participation'; Tharp and Gallimore (1998) describe 'assisted performance' and Mercer (1995) highlights ways in which children might be guided to 'construct knowledge'. In whatever way this learning process is described, there is an underlying assumption that the more competent other has an end-goal in mind.

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Tharp and Gallimore's suggestion that 'guided-reinvention' connotes both social learning and cognitive constructivist arguments, together with their additional suggestion that children do not invent language for themselves (Faulkner and Woodhead (1999), set the boundaries of this challenge facing deafblind people in their journey towards language. All naturally occurring languages have hearing or vision as their principal means of transfer and Vonen and Nafstad (1999) write that a natural tactile language has never developed anywhere in the world. So if deafblind children cannot construct a language for themselves and they cannot simply learn the language of the dominant culture around them, what kind of learning should be taking place and what does this say about the teaching processes involved?

Rogoff et al (1998) raise concerns that by being too heavily focussed on literacy and language skills suited to formal education settings, 'scaffolding' suggests a specific path that has to be followed. It must surely be open to even more criticism when we consider the barriers that exist for a deafblind person trying to access language. So perhaps an asymmetrical relationship that guides a deafblind person towards the language used by the communication partner is not the best model for the development of communication skills? Symmetrical relationships for deafblind people would appear to suggest a number of insurmountable barriers, so can the literature point us towards the kind of double-sided ZPD described by Brown (DbI Seminar, 2001), where in any interaction there is a ZPD for the deafblind person and a parallel ZPD for the communication partner? Perhaps the seeing-hearing person has just as much to learn from and about the deafblind person as the other way around.

Brownell and Carriger (1998) ask what kinds of cognitive conflict might be engendered in the expert who scaffolds the learning for a novice. However, whilst they consider that learning is taking place for both participants, they still see an asymmetrical relationship. Wood (1998) would also give precedence to the teacher's role, even though he suggests that teaching 'provides opportunities for the acquisition of knowledge'. Moll and Whitmore (1998) suggest a 'collective ZPD' where there is an interdependence of adults and children suggesting that the 'sociocultural system' is mutually created by teachers and learners. Tharp and Gallimore (1998) characterise the ZPD as a series of growing edges which are an expression of the child's activities and social relationships. (Faulkner and Woodhead (1999). So perhaps in establishing communication, we can see the possibility of blurring the distinction between the roles played by deafblind people and their communication partners.

But what is communication? Here it will be defined simply as partners trying to develop shared understanding. Göncü (1998) would describe this as intersubjectivity, 'the adoption of a shared focus of attention and agreement on the nature of

communication'. Redbroe and Souriau (2000) explore Trevarthen and Hubley's distinction between 'primary' and 'secondary' intersubjectivity, highlighting that at the primary stage, the emotions shared, the topic addressed and the utterances that are used all emerge from the 'togetherness between the two partners'. If, as Göncü (1998) suggests, intersubjectivity is achieved 'through recognition and coordination of intentions' then this does not immediately imply a move towards the language used by the communication partner. Indeed, how could the deafblind child agree to such a language if it is largely inaccessible? Instead, it leaves open possibilities of negotiating shared meanings and co-creating shared languages. Nadel and Camaioni (1993) have suggested that a communicative episode is 'an on-line process of adaptation to each other within which intentions and emotions are shared and negotiated'.

Göncü (1998) highlights the importance of 'prolepsis' in the achievement of intersubjectivity, where both participants make an effort to understand each other and the speaker presupposes that the listener has prior knowledge not yet introduced to the conversation. He describes the latter as 'based on faith in a mutually shared world'. Rogoff et al (1998) describe communication principles where the speaker should be sensitive to the perspective and knowledge of the listener and this is a theme taken up also by Stone (1998), who considers mutual trust as an essential element in the process of achieving intersubjectivity. Stone suggests further links between prolepsis and Rogoff et al's notion of guided participation (1998), arguing that adults and children need to find a common ground, allowing bridging between the known and the new to take place. Stone then argues for 'a fluid interpersonal process in which the participant's communicative exchanges serve to build a continually evolving mutual perspective on how to achieve the situation at hand'. This suggests a degree of symmetry in relationships far removed from Vygotsky's notion of the more competent other.

Symmetrical relationships are a core feature of co-creative communication (Nafstad and Redbroe, 1999) and Nafstad (2000) suggests one role for partners is to recognise the deafblind person simply as an extraordinary version of ourselves. This leads to equality within the relationship. Rogoff et al's suggestion of 'mutual adjustments in communication' that lead to bridging (1998), Tharp and Gallimore's 'continual adjustments' in direct response to the learner (1998) and Brownell and Carriger's consideration of ways in which learners jointly structure activities (1998), all point towards a recognition of important and equal roles played by both participants in a dyadic exchange. Schaffer (1996) too considers the active role that is taken by both participants in episodes of joint involvement. And although Moll and Whitmore (1998) recognise that emphasis is usually placed on the transmission of skills from adult to child, they suggest that a more transactional view of the ZPD is possible, 'one that focuses on the construction of meaning' and

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after all "seeking shared meaning is in the nature of human communication". (Rogoff et al, 1998).

Meadows (1999) argues for 'obvious variation' between individuals in their cognitive development, similar to arguments expressed by Wertsch and Tulviste (1998), who consider it "more appropriate to characterise the mental functioning of individuals in terms of 'heterogeneity'". Just as many writers highlight the developmental variations that occur across different cultures (Schaffer, 1996; Cole, 1998), then similarly we ought to consider differences that surely occur in ways in which people with dual sensory impairment learn to communicate. We should rise to the challenge of trying to 'capture the facts' about the developmental differences between seeing-hearing people and deafblind people, without 'falling prey to assumptions' that the language of the dominant culture is superior. (Wertsch and Tulviste, 1998).

With a backdrop that "culture is a medium not an independent variable" (Cole, 1998), Visser's comments (1999) about the 'old times' approach to language teaching with deafblind children might suggest that previously teachers viewed any sensory impairments as an 'independent variable' rather than an integral part of the child. However, it seems clear that a child's lack of hearing and sight can never be anything other than a medium through which all information passes. We should not view deafblindness, however, as a negative state of being in which sight and hearing are not there but instead as a positive state in which touch is the pre-eminent source of information. This immediately suggests ways in which communication should be channelled. If people bring who they already are to relationships they participate in (Stone, 1998; Brownell and Carriger, 1998), the odds will be unfairly stacked against the deafblind person if the communication partner is unwilling to see them as a co-contributor of communicative acts within that relationship. Brownell and Carriger (1998) wrote that what children take away from collaborations will differ as a function of what they brought to them. This could equally allow us to ask what a communication partner should bring to a relationship with a deafblind person if it is to result in a successful encounter that leads to shared understanding between the two participants.

Moll and Whitmore (1998) describe ways in which a teacher is able to 'participate' in a class, where guidance is embedded in activities and this seems reminiscent of Rødbroe and Souriau's advice that a partner should create a 'natural context' for communication development. (2000) Moll and Whitmore (1998) suggest a teacher should allow and promote power to be shared between herself and the learners. Trusting the learner is a central theme in this stance. It similarly lies at the root of Rødbroe and Souriau's suggestion that the partner should be sensitive to the contributions of the deafblind person, willing to both lead and be led. Similarly, Hoogsteder et al (1998) advise that in any analysis of learning the focus should not be

unidirectional. Joint regulation of an activity is a central feature and they offer three distinct modes of categorising the role distribution within interactions:

- playful – in which there is an equality of opportunities
- efficient and economic – where the adult controls and dominates the child
- didactic – which is in part asymmetrical as the adults monitors the actions of the child, but in part symmetrical because adult and child attempt to reach a common understanding.

Rødbroe and Souriau (2000) consider 'the natural way of learning is to play' so they emphasise the playful mode and indeed are critical of the field of deafblind education for its previous insistence on viewing communication as simply a message system. They might see this as the 'efficient and economic' mode where the adult attempts to impose language on a child, without necessarily being interested in the creation of 'sustained and joyful communicative episodes', which after all may be a child's initial goal. (Tharp and Gallimore, 1998). Rødbroe and Souriau (2000) advise that the responsibility for sustaining these episodes fundamentally rests with the communication partner.

Since both participants 'have to construct their goals ... on the spot' and these goals 'emerge out of the dyad's interaction itself' (Hoogsteder et al, 1998) it seems clear that by sustaining the interaction there will be increased possibilities for achieving emotional attunement, negotiating shared meanings and developing joint attention. There is no pre-defined way of doing this (Hoogsteder et al, 1998) and 'it will never be possible to create a programme indicating when and what to do in communicative events'. (Rødbroe and Souriau, 2000) A number of ways are suggested by which partners may expand upon utterances made by a deafblind person, in this way encouraging a continuation of communicative episodes. Best (2000) suggests that a competent partner will be 'able to 'read' the child and behave in a way similar enough for the child to experience connection – a self-other contingency'. This is reminiscent of Bruner's suggestion that a teacher should be 'leading by following'. (Wood, 1998) The competent communication partner's role then is not to guide the deafblind person to a given destination, but instead to follow the deafblind person's lead and in doing so co-create a new, negotiated way of communication.

Whilst asymmetrical relationships were the starting point for this literature review, there is a sense that symmetry may provide a more fruitful basis for co-creation communication. Nevertheless, there is a distinct role that the communication partner has to play but gaps in our current knowledge about exactly how the ZPD might apply to deafblind people leaves some unanswered questions about the exact nature of that role. Intriguing questions are posed about ways in which young, minimally verbal children may be able to recognise social and communicative clues to establish

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and repair shared reference and negotiate meanings. (Brownell and Carriger, 1998). There are also calls for further research into ways in which toddlers use non-verbal metacommunicative messages to develop shared pretend play language. (Göncü). Finally, Rogoff et al suggest that 'infants who are in almost constant skin-to-skin contact with their mothers may manage effective communication through tactile contact in squirming and postural changes'. (1998) Perhaps, deafblind people

are already skilled in recognising and using subtle tactile communication strategies and Brown's notion of a two-fold ZPD (DbI Seminar, 2001) may suggest that these are the skills which a communication partner needs to develop. Perhaps, symmetry will be achieved if the communication partner was to learn to perceive the world from a deafblind perspective, described by Nafstad and Rødbroe as an 'absolute subjection of oneself to the deafblind child's needs'. (1999)

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Holidays for the Deafblind

Ustronie Morskie, Poland, 16 – 23 August 2003

Dear Friends,

We have pleasure to invite you to holidays for deafblind people, this year taking place in Ustronie Morskie, a charming seaside town in the north of Poland. During your stay in Ustronie we'd like to offer a rich and interesting programme as regards recreation, tourism and relaxation, as well as a lot of attractions with a view to make your holidays in Poland diversified. We hope that the holidays in our country will enable you to meet your friends from previous vacations but also to get to know new deafblind people from all over Europe, to share your experiences and to make new friendships. At the same time we would like you to find out about our country's culture, its traditions and natural attributes.

Arrival

We suggest that all the participants of the holidays meet in Warsaw at the Polish Association of the Blind (9 Konwiktorska Street) on August 16th. In the Application Form we'd like you to specify where (the airport or the railway station) and what time you're arriving as it will make it easier for us to organize transportation by taxis to the meeting place. It's possible to arrive a day earlier (and to leave a day later) with extra cost for accommodation and board amounting to EURO 30 per day.

Language

In order to enable communication among the participants, during the holidays we'll be using the English language, so we would like the deafblind participants or their interpreters/guides to speak English.

Insurance

We'd like the participants to take care of the insurance on their journey and their stay in Poland as their own responsibility.



Place and accommodation

Ustronie Morskie is a charming Baltic town situated in the north of Poland about 500 km from Warsaw. It has a wide beach with fine clean sand and an easy and safe access to the sea. We offer accommodation in the Treatment and Rehabilitation Center of the Polish Association of the Blind KLIMCZOK, situated 150 m from the sea, in single, double or three-person rooms, each with a bathroom, balcony and phone. The center has a cafe, cafeteria and TV rooms. There is also friendly and smiling staff there.

Programme

During the holidays we offer many recreational, cultural and social attractions: trips to interesting and beautiful towns and villages, sightseeing, discos, art workshops, social games, water sports and many more activities which are described in detail in the Programme. The Programme that we propose can be slightly changed or modified, for example because of the weather. The number of people helping during the holidays depends on the number of deafblind participants and their guides taking part in the holidays.

Cost of holidays

The cost of the holidays including accommodation, full board and the programme implementation in Warsaw and in Ustronie Morskie amounts to EURO 30 a day. The transportation cost (road from Warsaw to Ustronie and return

journey and for trips while in Ustronie) amounts to EURO 10 a day. The total cost of the holidays amounts to EURO 280 (in case of accommodation in a single room – EURO 385).

Address of the center in Ustronie

Ośrodek Leczniczo-Rehabilitacyjny
Polskiego Związku Niewidomych
KLIMCZOK
ul. Okrzei 1
78-111 Ustronie Morskie
Poland
tel./fax 0048 94 35 15 565

If you are interested in taking part in the holidays for deafblind people in Poland, please familiarize yourselves with the Programme and fill up and send back the Application Form. If you know any deafblind people who might be interested in these holidays, please forward this message to them or send us their address. If you want to get more information or if you have any questions, please contact us:

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I hope to meet you soon in Poland.

Best regards,

Józef Wędruch

President of the Association for the Welfare of the Deafblind

Nordisk Kulturforbund for Døvblindfødte: The Nordic Culture Network



Nature sculpture classes for deafblind people at Johnsgård in Sømådalen, Norway



Working in stone.

Every year the Nordic Culture Network arranges courses for congenitally deafblind people in Sweden, Norway and Denmark. In 2003, four courses will be on offer. One will be in Sweden, one in Norway and two in Denmark. The course in Norway will be held in Sømådalen, a wonderful place deep in the countryside, where deafblind people have a lot of opportunities to join cultural activities, experience new things and make new friends. Jan Ole Johnsgaard, who has developed the course, tells us more.

Over the last five years we have hosted a class of deafblind born adults attending a sculpture class. It has been a great pleasure: all the hard work, all the shared experiences, all the fantastic results! These are things every one of us should have experienced. A Norwegian deafblind man said on the last day, last autumn, "I'm tired, I'm going home, but I'll

be back later". To watch him express those words made a huge impact on us all. There were silent tears on all faces: to be tired from hard work together with other people, that's enjoying life and to be aware of it.

I was not present when all participants had their last meeting to discuss the week. During the week the group had made a picnic place. Just simple seats surrounding a

bonfire. When I came along, there was a quiet mood over the group. No one wanted to leave. They were all captured in a silent togetherness. All equally participating in a common shared theme. This observation is and was a tremendous reward for being in this project, created by the Scandinavian parents association for those born deafblind.

Friendship.



Why Johnsgård?

Being a parent of a seventeen-year-old boy, born deafblind with Charge syndrome, it was natural to offer our place for one of the classes of the Culture school. Tormod, our son, was born and raised here in Sømådalen. He has attended the local school, and he will live here for the rest of his life. This is where he belongs, where his roots are. This is where his people are.

We are farmers and hosts of a campsite. The site is open around the year. The place is situated way up in the Norwegian mountains, about a four-hour drive north of Oslo.

Johnsgård is situated by Lake Langsjoen, at 1350 m



above sea level and is a magnet for those who love to hike. The sunrise viewed from the top is unforgettable. The place is at its most magical in March. Long cross-country skiing hikes entice us and we have about 70 km of ski slopes surrounding our place during winter.

Parents getting together

When meeting with other parents during Tormod's childhood years, we formed a group of families who started to meet frequently. We shared common problems and most of all common joy. We enjoyed each others company and have over the years established Johnsgård as our place to meet. It

started out with a week during the summer. This was twelve years ago. Over the years this has grown into prolonged summer weeks, autumn-break, Christmas, winter-break, Easter, weekends and so on. Some families have bought campers, some take a holiday house close by and others stay in our cabins.

It is of course possible for new families to join us. Every summer in week 28, we meet for a family week. We meet at the barbecue-house for dinner. This is the everyday meeting-point. During the week we go hiking, fishing, on beaver-safaris and so on. Some choose to go shopping at Røros. The deafblind people mingle with all these people, sisters and brothers, uncles and aunts,

grandparents and friends. Over the years the sisters and brothers especially have profited during these weeks. They have each other, a unique group of youngsters who share common experiences.

The nature sculpture week

There have been Swedish, Danish and Norwegian participants in this class. They come by car or plane. Each group have their own cabin (or cabins) during the week. They gather in the main house for all meals. At night all meet down by the lake for coffee and to talk through the day.

The first year a lot of work was put into re-sculpturing a pine tree. Each year a new branch is added to the "Trolltree". Every participant works with stone as the main material. Local stone is used mainly, but stone samples with different qualities have been tried out. Last year we tried out a soft stone which was easy to work on. The students learn how to handle different tools. They also participate in making displays for the sculptures when they are finished.

We have experienced, over the years, the development of those who have been here more than once. They recognise, they know what will happen next and they work hard. Some of them are hard to stop. Some work one shift and take a break the next. Some work three shifts a day!

At the end of the week we have a big dinner down by the lake. During the week each and every one will have contributed to the dinner. Some have been fishing, some milking, some have made butter and some have

Experience and collaboration – using the long rope.

It has been a great pleasure: all the hard work, all the shared experiences, all the fantastic results!

THE ARTS

picked berries. All this is voluntarily provided by all the participants. We eat, we sing and we even dance!

Its popular – everyone comes back again and again!

Eskild and Gry come back every year. They go out fishing every year. They know from earlier experiences that the nets go out in the lake in the evening, and they know what to expect the next morning. They even talk about this at home.

Every year is different. The dedicated people are always there. We just have to admire all the enthusiasm that the people working with our deafblind people put into their work. I think bringing all these people into a totally new situation, giving them new

angles to work with, creates some new experiences for everyone. Going on a trip together and sharing new experiences always brings out something new and unexpected. Two deafblind men found each other in working with a display. They built the display in stone together. They worked together making the ground even and firm, later putting stone to stone for the display, and finally putting the sculpture in place. They worked together, and they shared it. And they enjoyed that experience.

The sculpture park

All the work ends up in a sculpture park. The picnic place, the pound with a water-pump and a waterfall, the different sculptures and the

tree are connected together with a long rope running through the park. Each year something new adds to the old. It is important to come back to find earlier works. This Scandinavian project gives the opportunity to do just this. To put down a lot of shared effort and then being able to come back and find it just the way it was. That's making shared histories.

The Nordic Culture Network will have a "Network-morning" at the Canadian Conference in August 2003, where we are looking forward to telling the participants about this wonderful project.

Lone Poggioni is the contact for this Network. She can be contacted at enrico.lone@post.tele.dk

It is hard work to make sculptures!



The school in the station!

The railway station in General Pico hasn't seen a train for many years but it still has a regular stream of visitors. The School for the Blind now occupies the booking hall and waiting rooms. Its Headteacher, Beatriz Zoppi, tells us more ...

The School for the Blind in General Pico, in the North of La Pampa Province, began working with Deafblind and multi-handicapped children from 1993.

This School is part of the government system. The Ministry of Education in La Pampa undertakes initial level and special education.

A group of parents were asking for a service for their multi-handicapped children who did not have access to another school in our community. The school staff made a decision because we looked at this different population, and realised that the professional training that we received did not consider blindness related to other disabilities.

The Hilton Perkins Program was really helpful and through Graciela, Steve, and Mike we were able to accept an invitation to have professional development to learn about these children in 1991. Since then Hilton Perkins has provided continuity, not only with annual projects, but also with a relationship that has allowed us to work at a constant and progressive level. Now we know so many other important organisations too. I am studying at the University of Birmingham, on the MSI course, with the co-operation of FOAL and Hilton Perkins.



SCHOOL DEVELOPMENTS



Our teachers

Teachers like Fabiana, Diana, Gabriela, Nora, Analía, María Silvia, María Rosa, and Marina have enthusiasm, and are participating in the programme with consultants that visit us to share knowledge and support us in this distant place.

Our community school

We respect, consider and support the whole community. We have an Asociación Cooperadora, and A.S.C.A.R. (Association for deafblind people) is functioning in the same building. The Mayor and the local government recycled a wonderful building from 1910, when the English engineers came to our country to design the railways for trains. We moved there in 1998.

The pictures with this article are from the last meeting last year. The gardens have ancient trees, not only flowers!

For families

In 2003 parents will have more special events designed for them. The way to establish better services is long and hard, we all know, because of the unique needs

of this population, but we all also know that there is a big family of parents, professionals, deafblind and multi-handicapped adults and children trying to work together all over the world.



Beatriz Zoppi and her pupils.

"It is only in this place that he turned into an artist and became conscious of his own value"

At the Centre for Polish Sculpture artists and craftsmen are working alongside deafblind people to assist them in realising their creative potential. One of the outcomes of this process is a collection of beautiful and evocative sculpture. Ewa Niestorowicz, one of the artists who tutors on the workshop, describes the work ...

Since 1990 the Centre of Polish Sculpture in Oronsco has become the place for annual workshops designed for deafblind people. The exclusive material to be used in the workshops is clay. The deafblind people create huge forms by use of the ceramic method, based on creating an armature and then coating

the outer shell with clay several millimetres thick.

The sculpture workshops usually take two or three months during which all of the participants are supposed to sculpt throughout the whole day. Everyone who takes part in the workshops for the first time has to face three basic challenges. They have to look at:

- elements of applied art. This task offers the ability to learn techniques of sculpting, as well as to develop their own imaginative ideas
- portrait
- an abstract composition. The development and presentation of one's imagination is the prior aim of the task.

All the people taking part in the workshops for the second time can choose the subject of the sculpture on their own. Some of them have managed to create pieces of art of a really huge size, including ceramic chapels reaching even three or four meters!

The teachers responsible for the workshops tend not to interfere in the process of the sculpture's creation. In fact a few gestures made together with a deafblind person can plant the idea of a given task



into the mind of the participant, creating the basis for the future work. The purpose of this procedure aims at making the deafblind artists conscious of a vast variety of shapes which range from the very simple forms to the most amazing ones. The sculptures are sad and melancholic or just the opposite – funny and optimistic. What is most interesting, however, is the shape of the created sculpture.



Although in most cases we are able to communicate with the participants by means of finger spelling, surprisingly the use of any language appears to be redundant. During eleven years of the workshops we have worked with people unable to use any language at all and, as it turned out, explaining the task to any of the participants was never a problem.

Sometimes it happens that a given work is not of the best quality from the technical point of view. In such cases all you have to do is to suggest a different hand position during the process of moulding in order to provide a better control over the shape of the sculpture as well as its stability.

A journey

For deafblind people this is frequently the journey from the depths of despair, with feelings of helplessness and constant humiliation, through the fascination with the process of creation and the ability of self articulation, to a feeling of social usefulness. It also promotes an awakening of interest and admiration of others untouched by the problem of deafblindness.

This is the place where they discover their own potential. This is also the place where they become the artists and the creators.

The deafblind artists

Mirek Łuszczyński came to Oronsko in a very bad nervous condition. He had very limited means of communication. In fact almost none. Fortunately, it took only one day of the workshops to replace the usual tension and fear with joy and fascination! After the workshops had come to an

end, on his way back home, Mirek was crying, which gives the best commentary on the atmosphere of the workshops in general. It is only in this place that he turned into an artist and became conscious of his own value. During the workshops he moulded three sculptures which seem to be quite uncommon because of their shape and originality.

Personally, I had the pleasure to work with another participant of the workshops, Mr. Mieczysław Leszczyński. It was an even more difficult task because he had an additional disability in his hands. Thus, from the very onset I had to

'guide' his hands in order to make the sculpture function technically. It was Mr. Leszczyński, however, who made the decisions concerning the eventual shape of the work. Already, after a week, he was able to sculpt on his own and the amazing outcome of his work can be seen and admired.

Franciszek Wielgus devoted the whole of the workshops to the creation of his full-size self-portrait. He began with the spine and successively added ribs, bowels and a stomach.

Finally he covered it all with clay – a man, however, must be real anyway!

Explaining the task to any of the participants was never a problem.



Jan Wisniewski is a completely deafblind person whose life has included the tragic loss of his wife and son as well as the amputation of one leg. "I feel really happy when I sculpt" he confesses. He works in total concentration and his sculptures are the fruits of his profound inner life, contemplation, and prayer to God, with whom, as he reveals, he remains in constant contact by means of a daily conversation. "God made a man in clay, and awoke him to life" says another deafblind artist, Henryk Kowalczyk.

It is so difficult for us, the educated artists, to give sculptures life, but the deafblind people can do it almost effortlessly. Henryk Kowalczyk is the maker of the three metres high Babel Tower. It reaches heaven! The top of the sculpture forms the palm of the Mightiest. The labyrinths of stairs present the hard paths of men trying to reach God. The Babel Tower is a sort of a homage paid by its artist/ maker to God who, although He has taken away his sight and hearing, has also gifted

The Oronsko workshops provide us with a unique knowledge of the abilities of these creative people with an extreme limitation to their senses.



him with the ability to create and sculpt in clay – the material he started with himself.

The Oronsko workshops provide us with a unique knowledge of the abilities of these creative people with an extreme limitation to their senses. We have more than ten years of experience in teaching sculpture to deafblind people.

The sculpture teachers look for contact with others

The teachers are the qualified artists. Personally, I am a graduate of the Art Department (I am a painter), as well as the Department of Pedagogy where I specialised in blindness. I have taught sculpture since 1996. At present, I am working on my PhD thesis on the subject of

"The world in the minds and the sculpture of deafblind people". So, if you have any experience of a similar kind, I would be very grateful if you could shared it with me. I would appreciate all sorts of materials and documents concerning your artistic work with deafblind people.

If you are interested in any kind of co-operation we look forward to hearing from you. At the moment the organisation of the international workshops of sculpture remains only in the field of our dreams, but we hope, maybe with your help, we will achieve this. We offer professional fully qualified staff. There are also several deafblind people who have taken part in the workshops from the very onset and now, with the badge of experience, they are already able to teach others.



Going places!

The red-and-white cane for deafblind people in the Czech Republic

Jan Jakeš of the Association of the Deafblind, outlines the background to this landmark legislation in the Czech republic which will make going places easier and safer for deafblind people. It highlights the importance of having a "voice" that is clear and consistent and the value of working jointly with others who may hold similar views.

The red-and-white cane for deafblind people is defined as a "marking sign" of deafblind individuals by the Act regulating the road traffic, which came into effect on January 1, 2001. The use of the cane was introduced on January 31, 2001 by the regulation implementing the Act. Since 2002, red-and-white canes have been supplied upon ophthalmologist prescription and fully covered by medical insurance companies.

The red-and-white cane serves deafblind people as an important compensatory aid enabling them to orient and move freely in public places, streets, and crossings. So far, deafblind people have used the white cane, which has regularly been used as a marking sign of, and distinguishing device, for blind persons. That was the reason why the deafblind often found themselves in difficult situations, e.g. when they did not respond to drivers' signals at crossings or when they reacted strangely and inadequately to the help offered by other people. This has often led to misunderstandings and

sometimes endangered the safety of both the deafblind person and the others involved. Thanks to the cane with red and white stripes deafblind people can move more safely in towns, and in traffic. The red-and-white cane draws the public's attention to the fact that there is a deafblind person present, i.e. it serves as a signal that, in addition to orientation and mobility problems, a greater communication problem may be present.

Self confidence

Moreover, the red-and-white cane gives deafblind citizens a feeling of greater safety, self-assurance and self-confidence. It is an important symbol of their identity. It also brings more respect from the general public.

The background to the new regulation

The way leading to the introduction of the red-and-white cane was a long one and, at its very beginning, its end seemed to be very far away. The civic association



Jan Jakeš

of LORM – The Society for the Deafblind – was the first to tackle this problem upon the initiative of its deafblind clients. They discussed the necessity of having a specific marking sign during a psycho-rehabilitation session, which was led by Ms Vera Husáková, a clinical psychologist, in October 1993. The discussion resulted in requiring a yellow cane to be introduced for deafblind people.

Yellow cane

We started our investigation to find out whether the use of the white cane for the blind was based on legislation. We found out that the use of the white cane was maintained by custom. We also found out that the white cane was only mentioned in the road traffic regulations. At that time, questions connected with road traffic were the responsibility of the Ministry of the Interior. That was why we filed our official application for introducing the yellow cane as a special marking sign for the deafblind with the Ministry. This was done in the spring of 1996, at the time when the

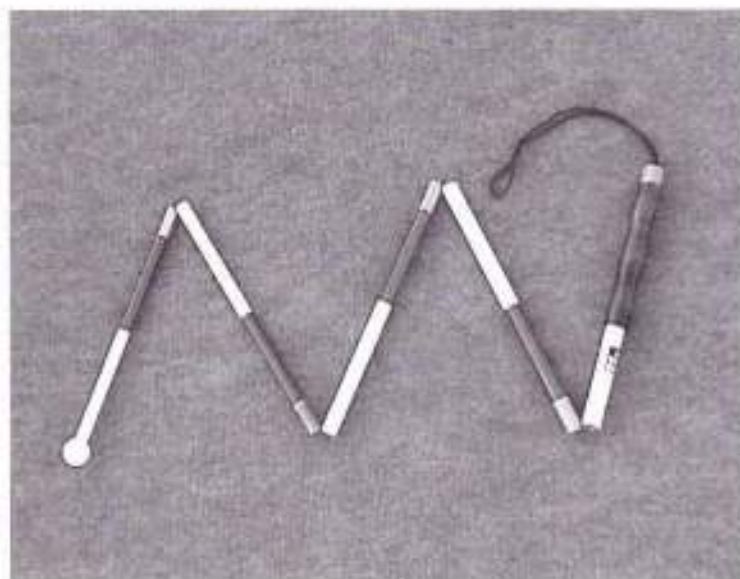
Ministry started preparing a new Bill on Road Traffic. We also contacted the Svárovský Company who produce canes for the blind and made an order for several samples of yellow canes, some of them with contrasting black stripes. We handed some of the samples over to the Ministry of the Interior.

Requests ignored

In 1997, road traffic became the responsibility of the Ministry of Transport and Communications, and our initiative was referred to that Ministry. Again we officially submitted our application regarding the recognition and introduction of the yellow cane as a marking sign to mark and distinguish the deafblind. Our initiative received no response. As it appeared later, our initiative was not included in the new bill at all; actually, a provision specifying an elementary drivers duty to respect persons using the white cane for the blind was also omitted in the new bill. The drafters of the bill did not at all consider the specific conditions of blind and deafblind people.

VIA is established ... and campaigning starts

Our affairs took a turn for the better with our new initiative. In 1999 we, together with several deafblind friends, established The Association of the Deafblind – VIA, a self-help organisation. We asked some parliamentary political parties for help in developing social inclusion of deafblind people. One of the political parties



organised a pre-election meeting for VIA members with its candidate for the Senate of the Parliament of the Czech Republic. At the meeting the deafblind people spoke about their situation and at the same time presented concrete suggestions for the improvement of the position and inclusion of deafblind people in society.

Among those who participated in the meeting was Ms Zuzana Roithová, Chairwoman of the Commission for Healthcare and Social Affairs of the Senate of the Parliament of the Czech Republic, who took interest in our problems. She admitted that she had not known about deafblindness and deafblind people, and that she had even hesitated over whether to participate in the meeting. She promised to help by putting our initiatives into practice, saying that she would need our technical knowledge and support. We specified four interconnected tasks, introduction of a special cane for the deafblind, recognition of the right to obtain hearing aids for both ears (binaural hearing correction) for

deafblind people with functional residual hearing, that these aids should be covered by medical insurance companies, and definition of the medical diagnosis of deafblindness. Our aim was to improve the orientation of the deafblind in their living environment by means of available technical aids.

Together with Ms Vera Husáková we prepared relevant data relating to individual tasks for Senator Roithová. In the case of hearing aids, an analysis of economic requirements was carried out from the point of view of medical insurance companies.

Joint action

The last part of our long way to the red-and-white cane began in January 2000. Senator Roithová invited us to participate in the talks with a representative of the Ministry of Transport and Communications on the proposed Bill to regulate road traffic. With respect to the already existing practice in some countries and to the international character of road traffic, it was decided to introduce the red-and-white

The red-and-white cane draws the public's attention to the fact that there is a deafblind person present ...

cane for the deafblind in the Czech Republic as well. Its appearance and design was prepared in co-operation with the Svárovský Company who produce canes for the blind. We also got a new ally – we informed representatives of the organisation of the blind of our activity. They had been trying to introduce the white cane for the blind into the Bill/Act. We offered them the opportunity to join our initiative. Our parliamentary campaign for the red-and-white cane could be extended into a campaign to include the white cane. When the Bill was discussed in Parliament, it was possible, with the support of most deputies, to amend the Bill to include a provision regarding the canes used as a special marking sign for the blind and deafblind. At the same time the Act imposed upon the Ministry of Transport and Communication a duty to prepare to implement legal regulations which would, among other things, specify the types and designs of the marking sign of blind and deafblind people. The aim was reached: since 31 January 2001 deafblind people in the Czech Republic can use the red-and-white cane.

Three more tasks remained: to ensure the right of deafblind people to get two hearing aids for binaural hearing, to secure the funding of the red-and-white cane and hearing aids for deafblind clients, and to define deafblindness for the purpose of distributing technical aids. For the purposes of solving these tasks, Senator Roithová formed a working expert group. Its members were recruited from among representatives of civic

associations of the deafblind and blind, from the Ministry of Transport and Communications, from the Ophthalmologist Society, the Otology and Phoniatrics sections of the Czech Society for Otolaryngology and from medical insurance companies. Our proposals served as a basis for the final document, which was called "Memorandum: the distribution of compensatory aids on the grounds of deafblindness". Representatives of the Learned Medical Societies (ORL and Ophthalmologist), medical insurance companies and deafblind people (LORM and Tyflo servis) signed the Memorandum in December 2001. The Memorandum defines principles, procedures and rules for the provision of technical compensatory aids to the deafblind.

On the basis of this Memorandum, since July 2002, deafblind clients with functional residual hearing have been entitled to receive two pieces of hearing aids for binaural reception covered by medical insurance companies. Medical insurance companies also cover the red-and-white canes.

Introducing the cane

The process of introducing the red-and-white cane, and of the social inclusion of the deafblind, is also supported by the expert and educational activities of the Pedagogical Faculty of Charles University in Prague. This was initiated by Mr Boris Titzl of the Department of Special Education. He dealt with the theory, provided grounds for,

and put into practice, the introduction of the topic of deafblindness into the course curricula of the modules of Special Education and Special Education in combination with Psychology. He himself, in his teaching, emphasises the importance of a specific approach to deafblind people and to specific aids and services for the deafblind, in particular the red-and-white cane and personal assistance. As a result of the above-mentioned activities, the author of this article teaches a course entitled "A Deafblind Person" at the Department of Special Education, Charles University thus educates specialists whose preparation is fully consistent with the latest development in the field of deafblindness in the Czech Republic.

Powerful lobbying wins results

The whole campaign has also had another significant side effect. It showed that even an allegedly unimportant small group of deafblind people can reach an important goal, and even help other people, as was demonstrated in the case of the white cane for the blind, when the lobbying of the representatives of the blind proved not to be sufficiently influential. It was also shown that such initiatives, whose aims can be easily identified by other organisations, can be successful. This is a promising springboard for other tasks that we have to deal with in connection to our inclusion in society.

With thanks for the translation into English by Jana Dvůřáková

This is a promising springboard for other tasks ...

Preliminary Invitation

**2nd European Family Conference
Slettestrand, Northern Jutland Denmark
20th - 26th June 2004**

A Family Event: "Listen to Me 2 - in Denmark"

Communication through Danish Culture and Nature

The Dbi Networks: Nordic Culture and Edon members, as well as Sense International and the Hilton/Perkins Programme are pleased to invite you to another international gathering of families.

The conference is for parents and their children from Western, Central and Eastern European countries.

As with other conferences in the past this conference will allow parents to discuss and exchange experiences and information on a wide range of issues concerning family life. The scientific planning committee is:

**Lone Poggioni (Dk)
Gill Morbey (UK)
Ursula Heinemann, (A)
Klaus Vilhelmsen (Dk)
Preben Gundersen (Dk)
William Green (I)
Frank Ulmer (Dk)
Ricard Lopez (E)**

This group are in the process of finalising the programme, which promises to create an exciting basis for discussion, and follow up the thoughts originating from the family event in Italy last year. The group are also looking for a new design for a Logo to represent the theme of "Listen to Me" as it is an event planned to take place every two years.

Dates

The arrival date is 20th June and departure on the 26th June 2004

Venue

Slettestrand holiday centre is in a beautiful part of Jutland and is only 250 metres from the sea. Travel is normally via Aalborg which is easily accessible by train, plane or car.

The centre offers a wide range of activities catering for many tastes. Accommodation can be in rooms for up to 4-5 people overlooking the sea. There are areas designed for children to play games. For further information about the centre can be found at www.slettestrand.dk

Participants

For the purposes of registration a "family" is up to four members: parents, their sensory impaired family member and one assistant of the families choice.

Programme outline

In fact there will be many parts to the programme:

- Parents meetings and conferences
- During these meetings their children and assistants will be

able to participate in artistic/musical activities designed for them and led by experienced artists in areas such as sculpture, music and dance, drama or handcrafts and much more according to needs and choice.

- Programme for siblings
- Visits to services for deafblind children and adults

There will be time for sight-seeing excursions, artistic activities or just simply having a break and relaxing all together.

Excursions can include shopping, boat trips etc.

Costs

The Planning Committee is in the process of examining funding possibilities to keep the price accessible for everyone and to ensure the participation of families from central and eastern European countries.

For more information, to suggest a logo design or to announce your interest please contact as soon as possible

Lone Poggioni
enrico-lone@post.tele.dk

Training courses and conferences at NUD 2004

Congenitally deafblind persons with CHARGE association

20 – 25 January

This training course will shed light on the complexity of CHARGE association and also point out the challenges this may cause in the planning and organisation of optimal conditions for learning and development. All staff categories may apply for participation.

Basic rehabilitation for persons with acquired deafblindness

1 – 6 March

The training course will provide knowledge about combined severe hearing and vision loss and its consequences for a person's communication, access to information and orientation and mobility. The training sessions will include a variety of simulation exercises and offer concrete examples. The target participants are workers in direct rehabilitation services.

Communication development in persons who are congenitally deafblind

14 – 26 March

The course will present the most up-dated information on interaction and communication with persons who are congenitally deafblind. The training course will be succeeded by case projects and network gatherings.

All categories of staff may apply for participation.

Training for supervisors/consultants in deafblind education

19 – 25 April

This gathering is the second part of a training course for supervisors/consultants in educational services for congenitally deafblind persons, which started in September 2003 concentrating on the assessment of congenitally deafblind persons. The focus of this course will be on how to create optimal conditions for communication and development. This session will also present and evaluate the participants' projects on assessment and individual education planning.

Children with hearing and vision impairments in pre-school and school programmes

12 – 15 May

This is a conference planned to present and discuss information about how to adapt the learning situations for children in pre-school and schools with acquired / developing deafblindness. Target participants are staff working in schools and kindergartens, as well as their supervisors.

Nordic Conference on Deafblindness

18 – 22 August

Every four years Nordic Staff Training Centre organises a conference on deafblindness. This event gathers together deafblind people, parents and staff and displays and discusses topics of relevance to those involved with current service provision.

Developing communication in congenitally deafblind children with cochlear implants

8 – 11 September

This conference is organised to present and discuss both theoretical and experience based knowledge on the development of communication in congenitally deafblind children who have cochlear implants.

Target participants are staff in pre-school and school programmes, as well as supervisors and consultants. This conference is open for participation also from other countries than the Nordic

Rehabilitation for persons with acquired deafblindness

27 September – 2 October

This training course will present and discuss different models of rehabilitation for persons who acquire deafblindness and also discuss relevant matters of both an ethical and practical nature. Target participants are all types of rehabilitation staff.

Education and work for persons with acquired deafblindness

10 – 13 November

This conference will shed light on the opportunities for education and other preparation for working life for young people with acquired deafblindness. It will also look at the modifications required of the working situation for people who become deafblind later in life.

Target participants are staff who have deafblind learners among their students and staff in work rehabilitation services for deafblind persons.

**For more detailed information, please contact us
Nordic Staff Training Centre for Deafblind Services
(NUD) nud@nud.dk**



Australia

New disability statistics



Mike Steer
reports on recent
developments in
Australia

Australia's population in June 2001 was 19.5 million. Of this number approximately 18% is estimated to have a disability or impairment. In December 2002, the Australian Institute for Health and Welfare (AIHW) released the publication, *Disability Support Services 2002: First national results on services provided under the CSDA*. The Commonwealth State Disability Agreement (CSDA) is the major disability services funding mechanism for cost-sharing between the Federal, State and Territory Governments.

The recently released report provides a summary

of data from the 2002 CSDA Minimum Data Set (MDS) 'snapshot' collection. On the 'snapshot' day, 65,809 consumers used 77,382 CSDA-funded services from 8,142 service outlets Australia-wide. Services used on the snapshot day were:

- ◆ accommodation support – 34%
- ◆ community access- 29%
- ◆ employment – 28%
- ◆ community support – 20%
- ◆ respite – 5%

The most accessed service types included:

- ◆ learning and life skills development (12,167 consumers)

- ◆ supported employment (11,898 consumers)
- ◆ group homes (9,528 consumers)

The most widely reported primary disability group was intellectual disability (39,909 consumers or 61%), followed by physical disability (8,002 consumers or 12%). Consumers reporting vision impairment as the primary disability were 1,716 (vision) and 170 (deafblind).

The report is available in PDF and word formats with main text available in HTML from: <http://www.aihw.gov.au/publications/index.cfm?type=detail&id=8267>

Teacher training

A Commonwealth Senate Report released just before Christmas has recommended mandatory training for all teacher aides and teachers in the education of students with disabilities. Recommendations appear in the Report of the Senate Employment, Workplace Relations and Education Committee on the *Inquiry into education of students with disabilities*. The Inquiry was established in response to concerns about the effectiveness of Commonwealth programs targeted at students with disabilities and whether the needs of those students were being met in the school sector and in post-secondary

education. The committee reported that evidence from many submissions and witnesses gave a clear impression that quality education for students with disabilities is a scarce commodity in schools generally.

There was much evidence of a serious and worsening skills shortage in Australia among teachers, who increasingly find students with disabilities assigned to their classes and are not prepared for this experience.

Further, most teachers already in service are unlikely to receive adequate professional development in this area. The training deficit is exacerbated by the decline

in the specialist knowledge base of the profession. The serious shortage of specialists in areas of sensory disabilities as well as in autism and learning disabilities was highlighted.

While the Commonwealth Government is not obliged to act on the report, the fact that Committee recommendations are supported by Government, Opposition and Democrat members of the Committee will give it weight.

The report (194 pages) can be viewed or downloaded as a single document or in sections at: www.aph.gov.au/senate/committees/eeet_ottel/ed_students_withdisabilities/report/index.htm

New audiology centre for Sydney

On August 29 last year, the Royal Institute for Deaf & Blind Children at North Rocks opened its new audiology centre.

The Centre was named after Jim Patrick, an Australian pioneer in the development of cochlear implant technology. It

provides state of the art testing facilities for children, including babies and children with additional disabilities.



Australia

continued

National Council News

More than 14,550 visits have been made to the Australian Deaf Blind Council (ADBC) Web site since it was set up in 1999. The site can be visited at <http://internex.net.au/dba>

Some of the recent business conducted by ADBC includes the following items:

- ◆ An Email group has been initiated for people with deafblindness nationwide

to seek feedback on deafblindness issues.

- ◆ ADBC seeks affiliation with the Australian Federation of Disability Organisations (AFDO)
- ◆ South Australian Deaf-Blind Association has agreed to launch National Deaf-Blind Awareness Week in 2003.

Topics being considered at current ADBC Committee

meetings include the following:

- ◆ Discussion on ways of increasing cooperation with Deafblind New Zealand
- ◆ ADBC establishment of a support group for parents of people with deafblindness
- ◆ Debate on a suitable logo for deafblindness in Australia

Sydney Harbour Bridge Climb

In July last year, ADBC members Heather Lawson and Joseph Heenan, who both have Usher Syndrome, with guides Carla Anderson and Bill Hynes from Sydney, climbed the spectacular Sydney Harbour Bridge. The huge bridge, together with the kangaroo, the boomerang and the Opera House is one of Australia's national icons. The climb was organised by BridgeClimb, a company that offers Sydney's visitors a small group adventure with guided climbs to the summit of the Harbour Bridge, day and night. Making their way over 1500 metres of arched

steel, to a point 134 metres above the busy Harbour, the intrepid Ozzie adventurers ventured across catwalks, scaled ladders and climbed across the main Bridge arch to the Harbour's north shore. This was the first time that BridgeClimb had encountered a group of deafblind people who used tactile signs, so an interpreter was provided.

The group's application had initially been rejected by BridgeClimb, but Heather and Joseph emailed its manager and expressed their disappointment. They explained that they would need only limited support to

safely make the climb. Because of their disappointment and the initial cancellation, BridgeClimb invited them back, and offered to cover the costs of their airfares from Melbourne to Sydney, one night's accommodation and the cost of the climb. Heather, at the successful completion of the climb said "We were treated royally".

A full report of the climb appears in the February issue of *ADBC Beacon*. A copy can be obtained by contacting ADBC Executive Officer, Bob Segrave at segrave@connexus.net.au

India

Computerized Braille Press for India



Dr. Bushan Punani reports on a new development:

A Computerized Braille Press was inaugurated at 10:30 a.m. on Saturday, 22nd February 2003 at the premises of Blind People's Association, Vastrapur. It was inaugurated by Dr. Tae-Sup Lee, International First Vice President of the Lions Clubs.

BPA has been operating a Braille Press since 1967 and has been producing Books and other material in Braille. But manual Braille printing is very irksome, monotonous, expensive and highly prone

to mistakes. It involves outdated processes and laborious techniques. As almost 10,000 blind children are studying, the need for Braille books is also high. The manual press could not meet these demands. BPA realized these shortcomings and decided to computerize the Braille Press.

On inquiry, BPA found that to have the equipment to do the job properly would cost a huge amount, so they appealed to the Lions Clubs

of Vastrapur & Ranip. They agreed to put the proposal before the Lions Club International Foundation. Fortunately, the proposal was accepted. The Lions Club International Foundation and the Indian American Education Foundation very kindly agreed to jointly sponsor the Equipment.

The new equipment is user-friendly, speedy, accurate and cost-effective, and is transforming our output!



Croatia



Martina Stabi

Dear friends,

I am writing this letter in the name of the Croatian Association of Deafblind Persons, Dodir, which has worked very hard lately on lobbying the Croatian Government and especially the National Committee on People with Disabilities in the Republic of Croatia on recognising deafblindness as a unique disability and recognising rights and services for deafblind people.

In different conversations with government officials we were asked to collect laws and regulations relating to deafblindness from different countries.

At the beginning of May,

the law on social services will be discussed in the Croatian Parliament and we are trying to include the definition of deafblindness and the right for services for deafblind people in it. This is why we need information on how these rights are provided in other European countries and other countries in the world.

We would like to ask you to send us any information you have on the following areas, no matter which language it is written in, by email or by fax: +385 1 48 75 431/432:

A Legislation, regulations or guidance with the exact reference numbers, years

when they were issued, exact articles where deafblindness is at least mentioned, and ways in which deafblind persons have rights to aids, guides/interpreters or personal assistants.

B Through which Ministries those rights are provided and how they are funded. How is participation by deafblind people included and how is the whole process administered? Thank you in advance.

Many regards and best wishes,

Martina Stabi, Social Worker, Development and Research Programme

Latin America



Ximena Serpa

"Grupo Brasil" Network 1997 - 2002

Professionals have been working in Brazil for many years. In fact it was one of the first countries to understand the needs of deafblind and multiply disabled people in the region.

"Grupo Brasil" is the main network in Latin America and was created as a non-governmental organization in 1997. It includes the Parents' Association and the Brazilian Deafblind Association and other institutions that work for deafblind and sensory impaired, multi-disabled persons in Brazil. "Grupo Brasil" has representatives in ten cities in the four big regions in the country.

Since 1997 it has held two very successful international conferences - the last one was in October 2002 - with the participation of local professionals and parents. International colleagues from Portugal, Chile, England, Colombia and Peru also attended. Three national

seminars and six regional ones have been held, also an Usher seminar, inviting parents, deafblind adults and professionals from all over the country.

The group has developed information campaigns and seminars with the Retina



Group of Sao Paulo and Medical Universities, the government and institutions, to inform the community about how to identify deafblind people with Usher.





To do this they have used posters and printed material all over the community. Training is also important and the group has trained different professionals from all over the country.

There is printed educational material, such as pamphlets on communication, Usher

syndrome, congenital and acquired deafblindness; a national website on deafblindness; a newspaper, and a book named "Two Senses: for the Senses and to the Senses" and a Manual For Parents and Teachers, printed by Sense International (Latin America) in Portuguese.

The group has maintained good contact with the government and the Educational Ministry and has developed and written materials, training programmes and projects for them.

For more information, please contact email: grpbrasil@ssol.com.br

Russia

Usher Forum Moscow



Irene Salomatina

In March 2003, Usher Forum Moscow brought together seventeen deafblind people and parents from Moscow, St. Petersburg and Ufa. The purpose of this meeting was to evaluate the impact of 18 months spent working to raise the profile of deafblind people and families in these cities, a project made possible thanks to funding from the UK's Department for International Development.

The seminar itself proved the value of a project which

has brought deafblind people closer together both within and between the three cities involved. Delegates from St. Petersburg were surprised that their colleagues from Ufa had never heard of cochlear implants. Conversely, the Ufa delegation – now just days away from registering themselves as an independent NGO – proved an inspiration to St. Petersburg delegates still struggling with Russian red tape. As one of the delegates reflected: "This

project will help us all in the future – in the past, we have not been good at asserting our rights."

The value of Russian deafblind people and families networking amongst themselves was re-enforced by another of the delegates who reflected: "I've seen videos of our British friends, but we need film of our own deafblind people – their reality, how they live."

If you would like to be in contact, please contact Irene Salomatina on irv@child.ru.

Nordic countries

NUD Training Course

"Correlations between problem behaviour and lack of communication in adult persons with congenital deafblindness"
5 – 9 November 2003 at Nordic Staff Training Centre for Deafblind Services, Dronninglund Denmark.

Chairs

Inger Rødbrøe from NUD Denmark and Randi Sørle from Norway

Objective

This training course will focus the group of congenitally deafblind adults who have problem behaviours. The correlation between problem behaviour and the lack of communication will be highlighted and discussed

from various perspectives. Strategies for treatment through educational approaches will be introduced and discussed in case-reports. Thus solutions to problem behaviour through development of communication will be aimed at.

Working formats

Working formats will be lectures on theoretical issues, and presentations of projects and case stories will give grounds for discussions both in plenary and group sessions.

Participants

The training course is planned for staff who are confronted with problem behaviour either in their direct work with congenitally

deafblind adults or as advisors or supervisors.

Dead-line for applications

Applications for participation must be submitted to NUD to be submitted to NUD by fax: + 45 96 47 16 16 or email: nud@nud.dk before **20 August 2003**

The preliminary

programme

includes contributions

from: Eva Hultengren, Denmark; Jude Nicholas, Norway; Inger Simonsen, Denmark; Siskoanneli Ruuskanen, Finland; Ivar Mæhle, Norway; Wenche Andersen, Norway; Karl Jacobsen, Norway; Randi Sørle, Norway; Paul Hart & Ian Noble, United Kingdom.

**Slovakia****Croatian visitors**

Janka Sarisska
writes:

The Deafblind School in Slovakia is expecting a visit in May 2003 from Croatian colleagues. The visitors intend to establish a school for deafblind children and they would like to learn as much as possible about running a school. Our school has prepared a programme for the whole week specially for them. They will take part

in educational activities in classrooms. They will have the opportunity to discuss the assessment of the student, about the individual educational plans, how the teacher organizes the educational work in classroom etc. They also will see the results of the projects that our students are undertaking at Presov

University and in the company which produces the toys. They will visit the psychologist who has cooperated with the school since it opening.

We hope that the visitors from Croatia will be stimulated by Slovak colleagues and that the study visit will be useful for the deafblind children in Croatia.

Getting together with the Czech Republik – another parents group

The cooperation between Slovakia and Czech Republic started in the year 2000 when we invited one family with a deafblind daughter and two teachers to take part in our Family Camp. There is the classroom of deafblind students in the Deaf School in the town of Olomouc and Czech colleagues from Olomouc were very keen to develop cooperation with school in Cervenica. After the Family Camp they visited the school, they spent a lot of time in classrooms, in the school's library and they had thousand questions!

When the same family visited the second Family Camp the parents were encouraged by the group of Slovak parents to start a parents association and

develop activities for their deafblind children in Czech Republic. The participation of a parent and pedagogues from Olomouc in the Dbl European Conference in Nordwijkerhout made the establishment of the parents association a reality. Since then they organized a small seminar for parents of deafblind children and professionals working in the field of deafness, deafblindness and multi-disability. They asked parents and professionals from Slovakia to share their experiences and prepare the presentations for this seminar.

Good cooperation can bear great fruits! In February 2003 the first country conference on deafblindness was organised with

international participation in Czech Republic. The role of this conference was to compare the situation of the services for the deafblind in the Czech Republic with services in Slovakia and other countries. The aim was also to persuade the representatives of the educational, social and health care areas that deafblind people have same rights as the rest of the population.

A Communiqué from the conference was sent to the government and it is hoped that a realisation that there should be a national commitment to the deafblind population, through the provision of the education, health service and social care, will help to enact the legislation for all this areas.

Latin America

Graciela Ferioli
reports:

Formal university training

Universities from Latin American are increasing their interest in meeting the needs of professionals who work with multi-handicapped children including those with deafblindness. During the last period, a second group of professionals from Colombia, Mexico,

Venezuela, Argentina and Chile got their masters degree at Universidad Metropolitana de Ciencias de la Educación - UMCE. A masters degree started in March at Universidad Presbiteriana Mackenzie in São Paulo. Brazilian ones are will start in July at Universidad Interamericana





Latin America

continued

de Costa Rica. These training programmes were able to develop through a

project collaboration between local universities, Fundación Once para

América Latina (FOAL) and Hilton Perkins Program of Perkins School for the Blind.

Three publications were translated into Spanish

The first is called "Calendars for Students with Multiple Impairments Including Deafblindness" by Robbie Blaha from Texas School for the Blind and Visually Impaired, USA.

The second one called "Perkins Activities Guide and Resources. A Manual for Teachers and Parents of



Perkins School for the Blind. These translations were made through support from Hilton Perkins Program through a grant from the Conrad N. Hilton Foundation and Fundación ONCE América Latina - FOAL. These publications will be distributed all over Latin America.

Calendarios



Para Estudiantes con Multiple Discapacidades Incluye Bordenes por Robbie Blaha

Students with Visual Impairment and Additional Disabilities" by Perkins School for the Blind.

The last called "In Celebration of Grandparenting, for Grandparents of Children with Visual Impairments" by Debra K. Chapuis from



Changing attitudes in Latin America

Every day people who work in deafblind education can observe how the community is changing its mind about the misconception of considering deafblind children not eligible for an education. That change is possible through the efforts of many international non-governmental organizations that are working in cooperation with local resources to support programmes and provide awareness-raising for parents' associations and also training professionals. The programmes are working hard to integrate children into regular community activities in order to change this misconception. In the photo in Venezuela, children are



drawing numbers in a raffle process to get funds from the

community to support future integration activities.



Catalan Countries

A request from
Ricard Lopez

To all Spanish speakers!

Ricard Lopez and his colleagues feel very strongly that Jan van Dijk's CD-ROM could be a very important and useful aid for the Hispanic communities. He wants to do everything that he can to make this possible. He has received a grant to translate all the content of the current English/Dutch CD-ROM into Spanish. The next stage is to modify the CD-ROM. The publisher has said that they would need to order between

250 and 400 CD-ROM at a cost of 35/40 Euros each to be able to cover the production costs. So, an investment is needed!

In order to make this a reality Ricard would like every organisation, professionals and individual families to indicate whether they would like to order in advance. Nobody will be asked to send any money until the orders reach the minimum number to make

the project financially viable. The final sale price will be the same to the cost, 35/40 Euros each, plus postage and handling.

Information about the English version of Dr. van Dijk's CD Rom can be found on the DB-LINK website: <http://www.tr.wou.edu/dblink/jvd-order.htm>

If you would like to register your interest please contact Ricard by email on: talking3@teleline.es

Scotland

"Partners in Communication" – a series of Seminars and practice development opportunities

Sense Scotland has been running a very successful series of Seminars and other practical events with support from the European Social Fund. It began with 2 days focussing on the theme "Everyone has a story to tell" – a title chosen to facilitate a discussion about communication, how it develops normally, why it goes wrong and what we can do about that.

Over the early part of this year the participants have looked at the areas of assessment, listening to

children, movement mobility and orientation and the communicating environment. They have also had a session on outdoor education and arts development, both areas that Sense Scotland has pioneered with great success.

Later on the course will cover record keeping and research developments and will conclude with a two day residential to review progress and take things forward.

The European dimension will be discussed with a contribution from Inger Rodbroe.



Some of the events are open to all – if you would like to hear more about them please contact:

Anne Marie McLaughlin
amclaughlin@sensescotland.org.uk
Phone: 0141 564 2444
Fax: 0141 564 2443
Text: 0141 564 2442

Kazakhstan

Timur
Timirkhanov

The Kazakh Foundation "Meyrim" is developing its own newspaper. Its new editor-in-chief is Timur Timirkhanov and he is looking for information on the widest range of subjects relating to deafblindness.

He would like news of 'links' to websites, rehabilitation information and methods of teaching deafblind children.

Please email to: timirkhanov@nursat.kz



Informal communication in the Meyrim Foundation.

Networks

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NETWORK NEWS

CHARGE

The past 18 months have been a very exciting time for the Network with the main focus on the CAUSE (CHARGE And Usher Syndrome in Europe) Project. The Project itself ended on 30 April 2003 but there is still some activity taking place regarding disseminating the information that was produced.

The highlight of the CAUSE Project was a conference held in the UK. This was a great success from both the Usher and CHARGE strands. David Brown, Tim Hartshorne, and Jacques Souriau were key speakers for CHARGE and they were very well received. Over a hundred people attended the CHARGE side of the event, including families and professionals from 12 different countries. We feel that this was a fantastic achievement.

At the end of the conference we held a 'Future of the Network' meeting. Here it was agreed that it would be worthwhile to aim to have a CHARGE conference attached to the next European Deafblind International (DbI) conference to be held in Slovakia in 2005. This is something that other groups have been doing in previous years – especially the Usher Network – with great success. One of the big advantages of this is that a lot of resources are already in place from the main conference, for example the venue, accommodation, advertising, etc.

It will also allow the CHARGE Network to do two major things: capitalise on the success of the CAUSE Project and plan for a

CHARGE conference to be attached to the World DbI Conference that will take place in 2007.

We hope that by 2007 the CHARGE Network will have grown into a fully functioning organisation and that the CHARGE Association will have a higher profile internationally. We still don't have definitive figures of how many people exist worldwide with CHARGE.

These dates may seem to be in the distant future but time flies. When we formalised the Network back in 1999 we had to overcome many obstacles because our ideas then just seemed like distant dreams. However, with help and support from a variety of individuals, organisations, parents and professionals, we have already started to realise those dreams. It took 4 years to plan for the CAUSE conference in the UK but it was worth the effort. The benefit to people with CHARGE and their families has been immeasurable. We believe that another conference in Slovakia in 2005 can do even more.



David Levey

David Levey

CHARGE Network Co-ordinator
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levey2000@aol.com
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United Kingdom

First Usher Study Group in North America

2-3 August 2003, Delta Meadowvale Hotel, Mississauga, Ontario, Canada

Since 1985 a group of people interested in improving knowledge and understanding of Usher syndrome has met every two or three years in Europe to share and learn from each other. The effects have been far reaching. Members have gone back focussed on Usher issues and keen to identify Usher families and to educate colleagues about the effects of the syndrome. With a World Dbl planned for Toronto 2003 it seemed right to also hold an Usher Study Group just before on Saturday and Sunday, 2nd-3rd August at the same venue.

As I write the aftermath of the war in Iraq continues to resonate around the world and the SARS virus makes people uneasy to travel especially to places where cases have been identified. In spite of this negative backdrop we are forging ahead with plans for a two day programme to look at 'Future implications of Usher Research Findings on Families' and at 'How

people with Usher Move Forward'.

In the next five to ten years families with Usher will be involved increasingly in the outcomes from current medical research. It is important that they understand what is happening and the implications for them both now and for future generations. On Day One of the Usher Study Group we will look at these implications in depth. To help lead us through *we have invited a number of scientists in the field*. Bronya speaks about her work with the Acadian Usher families in Louisiana, Medhi Sadeghi who has worked with Usher Families in Sweden gives a paper on hearing changes with people with Usher 2 A and also on vision changes in Usher 1, 2 and 3. Bill Kimberling from the Boys Town National Research Center, Omaha leads a discussion entitled 'Are clinical trials around the corner for people with Usher syndrome'?

On Day Two the emphasis is on lifestyle and on moving forward.



The Usher Peer Mentor Scheme where people with Usher are trained to act as mentors for others is described by co-ordinators Gloria Ward and Chris Sherlock. Anny Koppen discusses the changing training needs of staff who work with people with Usher.

A young woman, Rebecca Atkinson who has Type 2 Usher shares her plans and how she sees her life evolving.

We hope that the First Usher Study Group will attract people local to the Toronto area as well as those who will be coming from the world community who are interested in learning and sharing knowledge about this major cause of deafblindness in adults.

If all goes well we plan to highlight some of the papers in the next issue of Dbl.

Mary Guest: Secretary European Usher Study Group

Staff Development Network

We have been reporting in recent DBI reviews that this network is now working informally with people in contact to share ideas and resources. Although there was lots of commitment to do this at the last European Conference, colleagues have found it difficult to find time to maintain regular and widespread contact. Areas of interest identified were: training for people without a professional qualification during first

year of work; training for staff working with congenitally deafblind adults; and using technology as a training tool. The world conference in Canada is an opportunity to rekindle contacts and colleagues are invited to bring materials and ideas to share. Sense and Sense Scotland colleagues will bring information about Core Training Modules for year one, a Communication course for staff working with congenitally deafblind

adults and a (soon to be) university validated course for workers at a pre-degree level which looks at deafblindness across the spectrum. If any of these topics interest you or you have resources to share drop me an email and I will ensure contacts are exchanged before the conference to enable a get together during our time in Canada.

Virginia von Malachowski
Sense - email: vvonmal@aol.com

European Usher Syndrome Network (EUSN)



The CAUSE (CHARGE Association Usher Syndrome Europe) Project was set up to benefit two emerging networks recognised by Dbl; the CHARGE Family Support Group and the EUSN. The EUSN had two opportunities to organise meetings at the CAUSE conference in March 2003. The meetings were open to any interested conference delegates. The EUSN met twice during the conference, on 29 and 30 March.

Each meeting was attended by around fifty to sixty people, most of whom were Usher, plus some family members, friends and professionals. As a result, we are likely to at least double our membership. An election of officers will take place as an email vote within the near future. We also hope to confirm an Usher person as a representative of the group on Dbl Council.

Another opportunity to publicise the EUSN will arise shortly, as I will be giving a workshop presentation,

"Maintaining and expanding an Usher Network across Europe and beyond" at the Dbl world conference in Canada in August. Hopefully, we will be able to use this workshop to recruit more members across Europe and to form links with other Usher networks world-wide.

Marilyn Kilsby

National Usher Coordinator, Sense and Acting Treasurer of the EUSN
29 April 2003

Acquired Deafblindness Network



The co-ordinating group of the European Acquired DB network met in Oslo at the end of February. This was our first meeting since the highly successful 4th European Seminar of the Network in Zurich last October. It was also our first meeting without Anneke Balder as Chairperson. Anneke has moved on to new work in a different field and I have taken over as Chair of a newly enlarged co-ordinating group which now comprises Else-Marie Svingen (Norway), Marie Dominique Loussier (France), Catherine Woodtli (Switzerland), Henryk Riber and Else-Marie Jensen (Denmark) and myself, Ges Roulstone (UK).

The group worked through follow-up actions from the Zurich Seminar now that Swiss colleagues have completed the tasks of translating all the papers from German to English! Participants at Zurich were promised a report of the main outcomes and actions from the last seminar and this will be mailed out shortly. The co-ordinating group also agreed to send out to network members a summary of items discussed at our twice yearly meetings.

The main item of business concerned the process of initial planning for the next European Seminar in 2004. This will be held in the UK in late September/early

October 2004. Sense have agreed to host the seminar to mark the start of celebrations of Sense 50th Anniversary in 2005. The first announcement will be made this Summer to coincide with the Network Day at the World Conference in Canada in August but those interested in attending should note the approximate date in their diaries now!

Ges Roulstone

ges.roulstone@sense-east.org.uk

Communication Network report

No new event has taken place since the last report in this review. However, following up the Conference organised in Gothenburg by NUD on "Sensation, Perception and Meaning" and in line with our long term planning, a Mini-Seminar on Semiotic analysis is being prepared. It is going to take place at NUD, Dronninglund Castle, on the 1st and 2nd of May 2003. It is open to a selected group of researchers from the fields of congenital deafblindness and semiology.

The Communication Network is moving its focus from studying communication from the point of view of interaction, dialogue and intersubjective regulations to investigating how meaning is shared, conveyed and established during communicative episodes. This does not mean that we are changing subjects, or moving to another chapter. It means simply that we are discovering how the content of the exchanges is a deep and powerful element in the communication processes. When communicating with congenitally deafblind people, including in a mimetic (non linguistic) way, it seems that we are more effective when we elicit and support narratives, which are kind of story telling experiences which do not necessarily take the form of language but have a real potential for developing complexity, sustaining exchanges, forming a secure identity and integrating linguistic forms.

Two main concepts will be addressed during this seminar: "narratives" and "blending". The first one, which is related to story-telling, will be addressed from the point of view of the dynamics of the narrative structure as an interface between communicative partners and between an individual and his

or her experience of the world. The second concept ("blending") points at how, during communicative experiences, we use, in a fast, coherent and effective way, blends of various levels of experiences (for instance mimetic and linguistic expressions, or the elements of a previous narrative to qualify another one etc.) in order to make sense. This capacity to play with various types of expressions or knowledge is active in all human beings, including congenitally deafblind people. There can be a gap, or a contrast, between the linguistic competencies of an individual and his capacity to take part in "making sense" games.

These topics are both very simple and very complicated. They are simple when we see them naturally actualised in communicative experiences (they almost go unnoticed) ... but they are very difficult to describe and understand. However, it is our task to do so that people in contact with congenitally deafblind people cultivate the competencies related to the processes, which are pointed at by these concepts. We are much supported in this research by Per Aage Brandt from the University of Aarhus (DK) and Sarah Taub who is a researcher at the Gallaudet University (USA).

We hope this seminar will help carve out thematic material for a more inclusive international seminar in the future (for example in Paris in 2005) and that it will inspire further cross-over collaboration as regards research and development of knowledge.

It is important to mention that a lot of colleagues from all over Europe contributed to the dynamics of our quest for better communication with congenitally deafblind children and adults. They brought in their experience, their



data and their comments and we would like this to continue. We would also like to underline how NUD supports our work by organising or hosting events which contribute directly or indirectly to improving our knowledge on meaning-making. NUD will publish soon, on the WEB, texts that could be of interest to many colleagues. These texts will be edited under the title CNUS: Communication Network Updated Series.

Jacques Souriau

Books

Objects of Reference: their role in supporting learners with multiple disabilities

This is the proceedings of the national conference held at the School of Education, University of Birmingham in June last year. It includes the work of Marleen Janson, Liz Hodges, Laura Pease and Adam Ockelford. Copies are available, price £5 from: Mrs J Whittaker, The University of Birmingham, School of Education, Edgbaston, Birmingham B15 2TT, England

EDbN: European Deafblind Network

EDbN was originally set up to access funding from Europe for deafblindness projects.

One of its principles was to involve a parent or family representative, deafblind person and professional from each country. Equal importance was attached to the three groups. At one point EDbN managed a coordination grant from the EU and funded a secretariat which was run for many years by Lex Grandia and Ann Thestrup. It had a newsletter, organised annual meetings, seminars, and had many projects. Unfortunately the EU then decided to fund fewer European NGOs in the disability field. Last year, as expected, the EU did not provide a grant for EDbN. EDbN held a meeting in Brussels last May (within a social inclusion project) at which a strong feeling was expressed that something should be kept going. In Athens, in September 2002, this was confirmed and the decision was taken that a number of organisations and people would work together as the EDbN.

This strong wish for continuing EDbN was strongly expressed again at the family conference last October in Puglia, Italy, where many families came together and explained their need for a platform.

So in March 2003 the following group came together to discuss the possibility of keeping EDbN alive: Richard Hawkes (Sense International), Wolfgang Angermann (German Deafblind Consortium, Acting Chairman of EDbN), Ricard Lopez (Catalonia & Spanish Parents Association), William Green (Vice-President Dbl, Consultant at Lega Del Filo d'Oro, Italy), Ursula Heinemann (Austria, sibling of a deafblind brother, psychologist), Sue Brown (Head of Campaigns at Sense), Lucy Drescher (Campaigns Officer, Sense), Malcolm Matthews

(Director of CSI at Sense, UK professional representative on EdbN).

We discussed exactly what EDbN should do in the future and it was recognised that this would really depend on the opportunities that arose and the commitment that different organisations/individuals may be able to give. It was emphasised that one of the strongest assets of EDbN is that it is an organisation that brings together families, professionals and deafblind people. It was also recognised that both professionals and deafblind people have many other opportunities for coming together and so a key priority for EDbN must be to focus on families. Families need a strong EDbN as a driving force for networking and activities. However, it was reiterated that families would not be the only focus of EDbN. It would continue to look for opportunities for all three groups, whilst recognising that families should be the priority focus whenever possible.

There remains value in an organisation that involves professionals, families and deafblind people at a European level, i.e. EDbN, but in the future the key will be to work with and provide opportunities for networking for parents. Because of the impact of Europe within our own countries, we have also recognised the importance of campaigning at a European level.

The purpose of the meeting was to agree how Secretariat functions will be undertaken, to discuss campaigning, to agree priority areas, to look at communications (including the web and newsletter), and to agree membership of EDF. We also considered the link with Dbl including whether EDbN would like a place on Dbl Council (EdbN is a network of Dbl). It was agreed that Ursula would be EDbN's contact with Dbl and Ricard will be nominated for a place on Dbl Council. Ursula offered to work as a volunteer for a number of hours each week and Ricard suggested areas he would like to be involved too. Sense has offered to work on campaigning. The main focus of the campaigning work will be 'The recognition of deafblindness throughout Europe.'



EDbN meeting in March.

William and the Lega del Filo D'Oro and Richard and Sense International have committed themselves to being involved in trans-national activities and looking for funding.

Wolfgang has maintained the link with EDF and is willing to continue in this role.

The meeting allocated tasks as follows:

Sense:

- Campaigning
- Actively seeking funds (with Richard Hawkes & William Green)
- Encouraging participation in campaigns
- Disseminating information on campaigns

Ursula Heinemann (Network Co-ordinator):

- Managing administration for EdbN
- Responding to enquiries on a range of subjects related to deafblindness
- Encouraging participation
- Disseminating information
- Maintenance of files
- Responding to queries from members and outside organisations
- Coordination and support for meetings

Ricard Lopez:

- Website management
- Encouraging participation of families
- Dissemination of information in electronic formats
- Production of an EdbN clipboard and/or newsletter for dissemination throughout Europe
- Liaison with DbI (EdbN is a Council member of Deafblind International)

Wolfgang Angermann:

- Liaison with EDF
- Liaison with WFD
- Official Representative EdbN

All:

- Contributing to decisions about location of conferences
- Liaison with any conference-organising committees

- Campaigning will be led by Sense and will concentrate on explicit recognition of deafblindness in Europe.

It was noted that seminars and study days have been a part of EdbN activity in the past and similar events might be organised at some point in the future.

The Denmark Family Conference in 2004 might be an opportunity for the next EdbN meeting.

So this is the news for the moment from EdbN. We are not a group with financial security, but we want to keep our network alive with our dedication and motivation.

For information please contact:

Ursula Heinemann:
ursiheinemann@usa.net

EdbN introduces an E-group

EdbN have introduced an e-group to aid communication between members and to enable the sharing of documents, notification of events and more. This e-group may be useful to send all kind of messages to members ensuring, in this way, that everybody receives the information.

The e-group is accessible through the EdbN Home Page on the website. Please visit and take a look!

Ricard López, EdbN

A New Network for DbI



Siblings Network

Are you a sibling and interested in a discussion about your role as a sibling?

Having a deafblind brother or sister has a big impact on the lives of siblings. It is important that parents and professionals, as well as the deafblind brothers and sisters, realise this. Therefore a new network for siblings of deafblind children and adults has been started. A network, which welcomes all siblings and can offer support and guidance when things

are difficult and where experiences can be shared. Also where a discussion can take place about our role as a sibling and our role as a guardian when our parents cannot take care anymore.

The aims of the network will be to:

- establish contacts between siblings
- raise awareness among parents, the deafblind siblings and professionals
- form contact links with other networks (e.g. EdbN, DbI) and organisations

For the first two aims, we will use email and internet, as well as meetings and conferences, which we hope to organise ourselves as well.

We will make an application to become a DbI recognised network as soon as possible. This will help us to develop our third aim to form contact links with other networks and organisations.

If you are a sibling and interested in a discussion about your role as a sibling then please contact:

Sabine Kersten
Sabine_Kersten@hotmail.com

"Meyrim" is the gleam of hope!

Meyrim, is the Kazakh word that means kindness, charity and caress! This is the name chosen for the deafblind association. It's a very new organisation, just two years old, but full of confidence and ideas, and ambitious to develop further in supporting deafblind people in Kazakhstan. In this article Galina Frolova, President of "Meyrim" foundation, introduces the Foundation and gives a flavour of the work it is doing.

We can do a lot!

Our foundation "Meyrim" is only two years old, but we already have our own history. Though not all our wishes have come true, and though we still have difficulties, we'll look over the past with a bright sense of thankfulness.

It is the first, and only, organization in Kazakhstan which aims to provide help to all deafblind people as well as to their families.

In January 2001 we celebrated New Year together for the first time. Also, the Lonely Hearts Club for deafblind people was opened. In a small hall of the Kazakh Blind Society Leisure Centre 27 people gathered. A brilliant concert by deaf actors engendered a friendly holiday atmosphere on this special day. We all drank tea and took photos that reflected the joy of socializing. In short, the meeting was successful beyond all expectations. We believed in ourselves and in our strengths. We can do a lot!

Success gives wings to people

Unfortunately life doesn't consist of only holidays! Workdays began. We took a room in the Deaf Society and started working. Everything

was new for us: first meetings, interviews and publications, and the difficult search for a sponsor. As a reward for hard work, first results and first volunteers have come along. Success always gives wings to people!

We started working from point zero, having nothing but a vast wish to help those who cannot help themselves, and those who have to live "in another world". Deafblind people here are little known about, and only specialists, relatives and deafblind people themselves know all about the specific problems of these disabled people. For some time we've knocked at closed doors, shouting about our problems to bureaucrats who seem to be unable to listen to our concerns. But we do everything we can.

They trust us!

While we were going from one closed door to another, time had passed and another bright holiday came – International Women's Day. Our hard search for sponsors was a success this time and we were able to celebrate this day at a restaurant. In the main hall of the restaurant, as well as the deafblind people and their relatives, mass media representatives gathered. Casually dressed



Lyazzat, Vice President of 'Meyrim', answers questions.

people with happy smiles on their faces meant that all this didn't simply look like another charity dinner. The performance artist was watched by the whole staff of the restaurant, as hardly anyone had ever seen before how deaf people sing and dance. The staff of the restaurant were invited to judge the cookery competition that was organized in the meantime! Every deafblind person received a present at the end of the meeting, but the biggest present was received by us, the organizers of such a meeting, seeing happy and smiling faces of our new friends and their confidence. They trust us!

The main dream for us is to create a rehabilitation centre ...

Registration

The day had come, when 4 people of the same mind met together, signed the constituent agreement and passed the necessary documents to the justice department for the state registration of the foundation. Founder members of the fund included a rehabilitation specialist of the Kazakh Blind Society, a blind man, a businessman, and me, the author of this article, deafblind, but who had residual vision at that time. As a person who understands deafblind people well and

knows their problems from within. I was invited to be foundation president.

By March 2001 our foundation had successfully passed state registration. This day is our official birthday – the Voluntary Foundation for Social Support and Rehabilitation of Deafblind People – “Meyrim”. This word, translated from Kazakh, means kindness, charity, caress. This is such good news, but meanwhile, this means responsibility and loads of hard work and difficulties for us to face. We have a new, more comfortable room, rented for free by KBS, stationery, given to us after publication in local newspaper “Almaty Tonight”. But our own account is in the red, and our enthusiasm is frequently clouded by different obstacles, particularly our search for sponsors; and, of course, a vast wish to help those who cannot help themselves.

100 people identified

By the time our fund had been registered we had found more than 100 deafblind people in Almaty. There are a lot of deafblind people in other regions of Kazakhstan, but we do not know the numbers because they're not organized.

Happiness and pain

Just three months after registration, the presentation of the fund was held. Such a problem as deafblindness is “discovered”, as almost nobody had heard about it!

Then again, our holiday finished and weekdays started. For most of us every day of the week is full of unbearable pain that borders on despair, looking at

seriously ill children. For example: beautiful, totally deaf, twin sisters suffering from Usher syndrome. 15-year-old Khalida's visual field is narrowing, bordering on critical point. Three year old Kamila, has already had a serious diagnosis as retinitis pigmentosa. Another example is thin 11-year-old Elina and 5-year-old Kolya, suffering from rubella since they were born. And their mothers, who are always close by their children, for the time being do not even know about their children's serious condition, have not understood their children's diagnosis, and refuse to listen to the doctors' death sentence on their children. They are fighting for their children's lives. What disasters are waiting deafblind children in the future? When will it become possible to help all of them? This is known only to God.

While we don't know the answer, every Friday the Lonely Hearts Club for deafblind people is held in our small, sometimes overcrowded room. Hither everybody comes who needs to socialize and meet with friends, to discuss everyday problems, to have a heart-to-heart talk!

The end of our first year ... and thanks!

Worrying and caring about people, the first year of our work has passed. We celebrated our foundation's birthday at Nauryz, Turkish New Year, the holiday of new spring. In a competition, organized by KSB, we won 2nd place among 11 other collectives. We also took part in other competitions.

Our holidays, meetings, small presents to society members became possible

only with our sponsors' help. We thank our sponsors greatly for their worthy help for our activities.

Thank you for the help we are receiving

Firstly, we want to thank the Canadian Embassy in Kazakhstan, the telecommunications company “Nursat” and a young businessman, Alexander, who always helps us materially as well as undertaking to represent our foundation in governmental organizations. Also, Aimag Urazimov, director of “Cardinal” leisure centre.

Our future

We've got great plans for the future, and in spite of the fact that our foundation is quite young, we have the chance to realize these plans. The main dream for us is to create a rehabilitation centre, which will provide all kinds of services which are vital for deafblind people. At the moment in Kazakhstan there isn't any such centre. At the present moment a person, who lives in Kazakhstan and suddenly loses his hearing and vision, doesn't have access to a basic psychological or medical service. They have to rely solely on themselves to overcome difficulties that came like a bolt from the blue. They have to tackle all rehabilitation works and surmount psychological obstacles. Furthermore, they don't receive any outgoing help or technical equipment.

Our aim is to provide the necessary support to all of the deafblind people in Kazakhstan.

Galina Frolova

“Meyrim” is the first, and only, organization in Kazakhstan which aims to provide help to all deafblind people as well as to their families.

Challenging Behaviour, NO. Challenging Communication, YES.

David Levey, CHARGE Network Co-ordinator, gives a father's revised perspective of CHARGE Syndrome following ground-breaking presentations at the CAUSE Conference. (CAUSE = CHARGE And Usher Syndrome in Europe)



David Levey

CHARGE Syndrome is now a major cause of congenital deafblindness and multi-sensory impairment in the world today. The early years following birth usually involve life saving surgery for the child, and life changing adjustments for the parents. Once the physical challenges become more 'manageable' only then do the deeper challenges fully emerge. These tend to fall into the categories of behaviour and communication. It was at the CAUSE Conference that I finally realised that these two aspects of CHARGE are inseparable.

Following on from the incredibly detailed and informative talks given by the speakers at the CAUSE

Conference I came to the conclusion that I no longer wish to apply the term 'challenging behaviour' to my son, Joshua. Although I can understand how this 'label' has evolved over time I now see that it has not helped improve my relationship with him in any way. Why?

The three main speakers on CHARGE at the Conference were David Brown, Tim Hartshorne, and Jacques Souriau. Each dealt with the topics of Sensory Integration, Behaviour, and Communication, respectively.

A small quote from each of their talks will give you some indication of how I came to my conclusions regarding my relationship with Joshua who is now 10 years old.

David Brown

"... difficulties with expressing themselves, or the constant experience of having their expressive communications misinterpreted, can lead some children to give up, or to resort to explosive behaviours that may be construed as unpredictable or irrational."

Tim Hartshorne

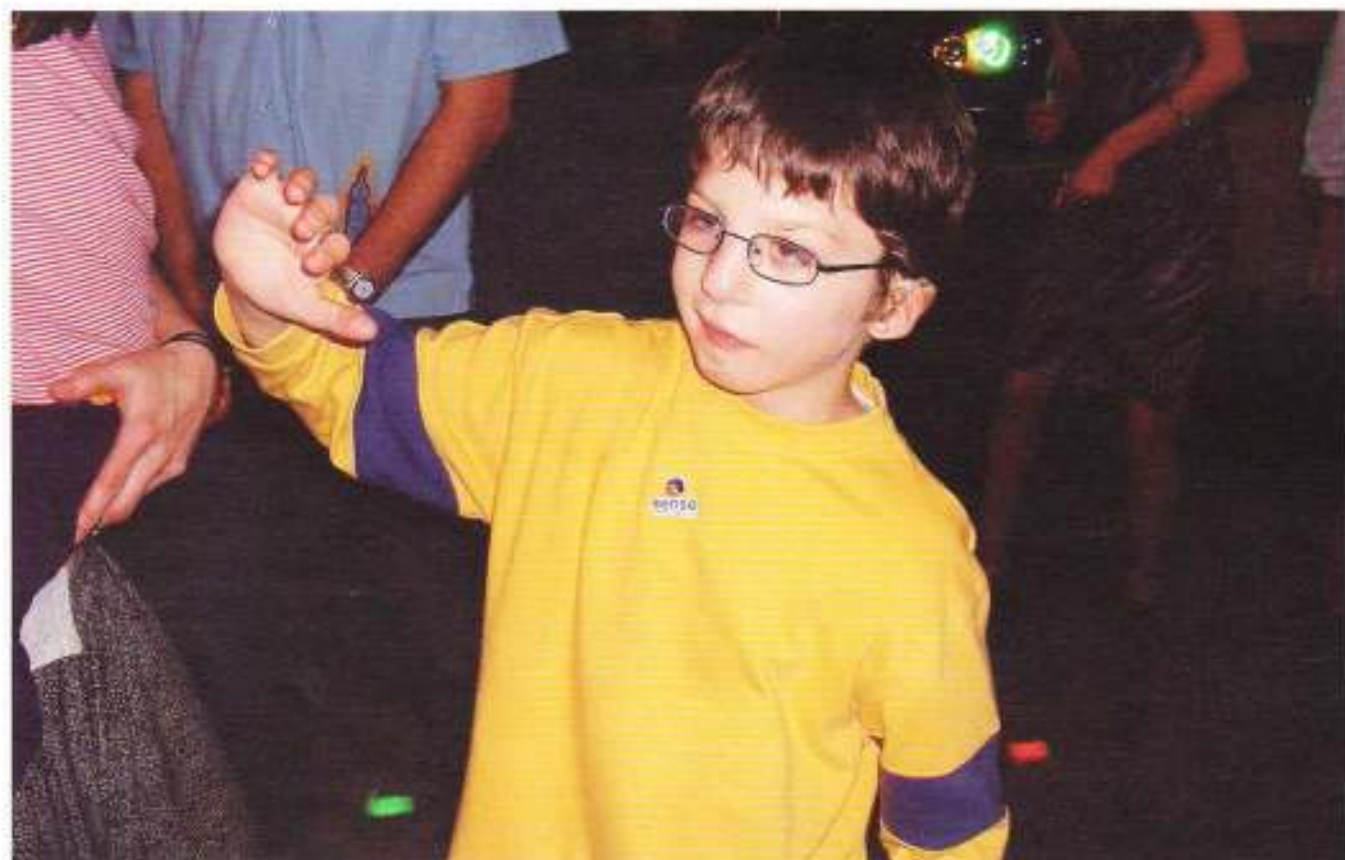
"All behaviour has a purpose, all behaviour is communication"

Jacques Souriau

"It is very much the case that support based on the communication needs of the person with CHARGE, rather than based on the ideas and thinking of the partner involved with them, will yield better outcomes ..."



Joshua and his aunt.



Dancing at the CAUSE conference.

Each of the speakers was able to use their extensive knowledge, built up over many years of experience and research, to paint a picture that any parent with a child who has CHARGE would instantly recognise. These presentations didn't simply overlap with each other. Rather, they interwove and showed the complexity of CHARGE, and gave a three dimensional quality to the interplay of behaviour and communication. I have chosen these key statements from each of the speakers because together they made me realise that I had been approaching Joshua from the wrong direction. That is, I was tending to focus far more on his behaviour rather than on his attempts at effective communication. No wonder then that many times we have ended up in an argument!

I personally know the terrible feeling of frustration when someone doesn't understand me. This has to be one of the most undesirable experiences I can ever imagine. How then must it feel for someone who has CHARGE? In addition to

deafblindness and multi-sensory impairment they may well have a variety of other physical problems that affect their ability to communicate.

The CAUSE conference showed the incredible variety of communication strategies used by people with CHARGE and also with Usher Syndrome. I could also see the wide variety of behaviours that we as a species exhibit. With or without a syndrome we are quite an odd looking lot if you take the time to sit back and observe us!

Not 'Challenging Behaviour' but 'Challenging Communication'

'Challenging behaviour' is a generally accepted term now, and I can see why it is used, but as a father of a little boy with CHARGE I feel that 'challenging communication' is a more positive and certainly more useful term of reference. It helps to keep me focused on what Joshua is trying to

achieve rather than on what I do not want him to do. It takes some of the angst out of what can often be an exhausting process – being a father. As I struggle to incorporate this new way of thinking I try to keep reminding myself that all communication is challenging. Even the most eloquent and confident people often get it wrong.

References: Presentations for CAUSE Conference, Hinckley, England – March 2003

David Brown, California Deaf-Blind Services, USA, *"Some behavioural implications of sensory difficulties found in children with CHARGE Syndrome"*

Tim Hartshorne, Professor of Psychology, Central Michigan University, USA, *"Challenging Behaviour in CHARGE Syndrome", "Behaviour as Communication: The Function of Challenging Behaviour"*

Jacques Souriau, Director, Cresam, France, *"CHARGE and Communication"*

Third Spanish encounter of families with deafblind children: Pontevedra, 28th – 31st July 2002

Deafblindness is a disability that generates specific necessities and attention from the ones suffering them and depending on the affection degree, the attention necessities can get to be very demanding for the family, and in most of the occasions it is very difficult to arrange the attention that this child requires and the attention that the rest of the members demand. For this reason the family needs aid. Ana Alvarez: necessities of the families with deafblind children, 2002.

Background

At APASCIDE we are clear that these family encounters are a great aid for families. Although we recommend meeting every two years, for various reasons the last one took place three years ago in 2001. However, we hope to repeat it in 2004.

The preparations and the place of the encounter

The encounter was organised by APASCIDE thanks to a grant from FUNDACION ONCE and the collaboration of CRE (Educative Resources Centre) Santiago Apóstol of ONCE in Pontevedra.

The number of participants

Twenty-five families from all over Spain participated. Six Galician families participated for the first time. The age of the deafblind children varied between seven months and forty-one years old; this means that there was a wide representation of different problems. Thirty-four wonderful volunteers helped us to make the encounter possible. The organisation and co-ordination of the event was carried out by eleven people. Altogether one hundred and forty-one people participated and in addition to the benefit of participating, they also made a lot of long-term friends and links.

Opening and report on APASCIDE

The encounter started with the emotive reading of Norman Brown's article "Celebrating the aims" (see bulletin APASCIDE # 8) by Dolores

Romero. The "Programme of attention to caring families" had special relevance; this programme was subsidised by the Ministry of Work and Welfare Affairs whose priorities are:

- ◆ To give support to families whose deafblind children are not being attended to. It is often the case that children with associated disabilities have some difficulties in being treated as deafblind.
- ◆ That long period during the summer when deafblind children and young people are particularly isolated from everything.

Andalucía is the main beneficiary of the work of the Ministry of Work and Welfare Affairs because of the great amount of cases in that region. Due to the lack of resources all over the country, one of our aims is to obtain more financing. The Junta of Andalucía and, to a lesser extent, the Xunta of Galicia are going to collaborate.

Report: the needs of the families with deafblind children – workshop

Ana Alvarez, co-ordinator of the programme of Support to the Caring Families and psychologist in APASCIDE, said "the family needs help and the projects and activities of APASCIDE try to give an answer to this reality". The most important project is the one of "Support to the Caring Families with deafblind children", subsidised by the Ministry of Work and Welfare Affairs.

Helped by Isabel Paredes, a social worker in APASCIDE, a workshop for parents was carried out. They looked at five practical cases in groups; the diagnosis, the familiar reorganisation of the families, the siblings of the deafblind child, the schooling of the deafblind child and the questions: What can we do? What kind of provision can we look for after they have left school?



José María Prieto helped by Pepe Tirado.

Report: The deafblind person and their stages of development

Mrs. Pilar Gómez Viñas, co-ordinator of Programs for deafblind people in ONCE, emphasised that "the perception of a deafblind person is different from ours. We must make an effort to understand their messages to us from the perspective of their image of the world".

Report: Hearing loss in deafblind people, prostheses and implants

Dr. Carlos Cenjor (Jiménez Díaz Foundation) made his speech on "Cochlear implants" and said: "nowadays they are effective, safe and lasting devices" and "presently the implantation in the ear with better hearing is recommended because, having been more stimulated, the results obtained are much better".

Report: The project of the centre for APASCIDE's deafblind people

Mrs. Dolores Romero, APASCIDE's President, spoke about the preliminary project of the first residential and occupational Spanish Centre for deafblind young people and adults. Spain does not have a centre for deafblind people older than 18 years and it is essential to plan for the development of a personalised project for every deafblind person. The aims are:

- 1 To continue with all aspects of training for deafblind people, and
- 2 To obtain a higher degree of possible autonomy for every person.

The centre should be:

- A reference point for the whole of Spain, and
- A training centre for professional staff and volunteers.

Report: My life experience as a deafblind person

José M^a is a famous Galician sculptor, and an example for everybody because he showed how independent a deafblind person can be when they have the necessary aids. His speech was really emotive and all of us identified with the



Noelia and Clara with volunteers.

problems he explained. One particular example that touched us was the description of a trip by plane during which he was abandoned for 6 hours in an airport because the people who should have looked after him ignored his disability. He showed his affection and support to our project of the centre.

The activities of the deafblind children and young people

The co-ordinators of the association took good care of the activities carried out by the children and young people. The specific characteristics of each participant were taken into account. Each one had an experienced and exclusive volunteer, selected on the basis of their specific communication and interaction needs.

The situation in Galicia

Recently deafblind children, and young people detected as deafblind people, have gone from a specific classroom to being integrated with other children. The number of experienced professionals in deafblindness is not enough and the number of specialised professionals needs to be increased urgently. In order to counteract this problem, APASCIDE has presented a project to the "Consellería de Asuntos Sociais of the Xunta of Galicia" for the first time.

The Volunteers

After our children, the volunteers are the most important people in our lives. Without them, none of our deafblind children would participate in any extra-school activity. Meeting together with other families would not be possible either. They give our children not only time and love, but also competent interaction with the world and activities. Although they are volunteers, they are also competent professionals. There is no time for anecdotes but let me tell them: Thank you very much, we could not manage without you.

Conclusions of the Encounter of the Families

The conclusions were the following:

- 1 Government Administrations should officially recognise deafblindness as a specific disability.
- 2 The first problem of deafblind people is the lack of communication.
- 3 The second one is the fight for personal autonomy.
- 4 Professional one-to-one support is essential.
- 5 The creation of a specific centre of reference for deafblindness is a strategic necessity.
- 6 Specific professionals trained in deafblindness are needed.

Ricard Lopez (talking3@telefon.es)
Clara's father, Catalonia & Spain
APSOECAT & APASCIDE

Thanks to Mike!

Sense International would not be the organisation it is today were it not for Mike Collins. A strange comment to make perhaps, but an honest one. Ever since we were created in 1994, Mike has offered advice, support and guidance, both to the organisation and also to me personally. He really has been a mentor in every sense of the word.

For much of this time Mike has been President of DbI and Sense International has been running the Secretariat. It has been a difficult and challenging time for DbI in many ways, yet under Mike's leadership the organisation has gone from strength to

strength. He makes it a privilege to be involved in DbI and when he hands over to a new President he will have left a great foundation on which to further develop DbI in the years to come.

It has been an honour to have worked so closely with Mike and I am sure that all of us, who have had this opportunity, have learned an enormous amount from him. He is a great man and I am proud to regard myself as his friend. I hope to retain this strong connection with Mike and I know that DbI will want to continue to benefit from his skills and knowledge in the future."

Richard Hawkes

"Since I was accepted into the international deafblind family I have known three presidents of I.A.E.D.B. or DbI. Mike was the tallest! The tall person can take big steps and reach into the far distance. I think that during his presidency Mike has reached out in all directions and enlarged the deafblind family from west to east and from north to south.

Mike, your heart was, and is, able to listen to everybody."

Janka Larisska



"As a former DbI President, I had the pleasure of collaborating with Mike as Vice-President. He was not only "Vice" but also "Wise" (do excuse me for this poor pun). At that time, DbI was growing very quickly and the constitution was no longer suitable. Mike's serenity and efficiency were needed for dealing with this difficult situation and preparing a new constitution. Since that time, a lot of activities have developed under the umbrella of DbI. In spite of this new complexity, Mike, as President, managed to encourage all the groups, countries and networks to work together smoothly and efficiently. His capacity to listen to everybody and to be so well organised has made DbI an organisation appreciated by everyone in the field of deafblindness."

Jacques Souriau

"I have the pleasure of knowing Mr. Mike J. Collins as President of the Deafblind International as well as Director, Hilton/Perkins Programme. He is a true professional worker and a very dedicated Administrator, Mike is very well known among workers with people who have multiple disabilities with visual impairment. A very unassuming, down to earth and a simple personality, Mike commands excellent respect among fellow-workers around the world.

He has always been very keen on promoting services for deafblind people in developing countries. He extended the fullest co-operation, support and guidance when the first DbI-ICEVI Asian Conference was organized at Ahmedabad during 8-13 February, 2000. He also played an instrumental role in initiating a variety of programmes in the developing world for the MDVI children.

Even in a remote part of Eastern China, the Principal of the School for the Deaf and the Blind, Kunming, Yunnan Province knew about Mike's interest in promoting services in that province. I was very proud to learn that people, even in this remote part of the world, knew about the Deafblind International and its charismatic President. The deafblind people of the developing world will always remain indebted to Mike for his variety of initiatives on promoting services in this part of the world.

I specially appreciate the democratic manner in which Mike conducts the meetings of the World Council of the Deafblind International. His adopts a very professional approach of when providing the agenda, seeking comments in advance on agenda items, following the agenda in a true spirit and giving an opportunity to each and every member to present his/her point of view on each item. I felt honoured when he agreed to convene a meeting of the World Council at Ahmedabad, at the Blind People's Association, immediately following the DbI Asian Conference. Due to this bold initiative, the members of the World Council could appreciate needs and aspirations of persons with deafblindness in the developing world.

It has been my pride and privilege to work under the dynamic leadership of Mike. I shall continue to look forward to receiving guidance from him in respect of initiating and promoting services for special needs children in the developing countries of the world. Due to his pleasing personality, depth of knowledge and leadership qualities, Mike has become friend, philosopher & guide to many professional workers around the world.

Bushan Punani

"The voice of a departing president via Tom Waits"

all I need is my railroad boots
and my leather jacket
as I say goodbye to DbI
although my heart is breaking

I will feel my way
through the darkened hall
and into the morning
The hobos at the freight -yard
keep the fires burning

Jesus Christ this goddamn rain
could someone put me on a train

and everything is turning blue now
there is nothing I can do now
as I say goodbye to DbI
you will find another soldier ...

In true gratitude ... Colleagues in Oslo



How to define deafblindness? An attempt at a synthesis



Jan Jakeš

In this article, Jan Jakeš, who is Chairman of VIA, The Association of the Deafblind, and also a part-time teacher in the Department of Special Education of the Charles University in Prague, presents his ideas for discussion on the definition of Deafblindness.

What is deafblindness?

We can find a lot of different definitions and descriptions of the concept of deafblindness. Attempts are being made to distinguish deafblindness from other sensory disabilities, with plenty of discussion to fuel the debate. At a very dictionary level it seems clear what deafblindness is. It is only when we arrive at the real situation, in human terms, that great difficulties arise. There are a variety of different opinions held by authorities and professionals, and also by deafblind individuals and their families, friends and carers. So the question is, *who is deafblind?* Is it when a person recognizes that his or her own situation is so serious that he or she says: I am deafblind? Is it when we can recognize that somebody else is deafblind? We hardly need to think about definitions if we are able to support deafblind people on an individual basis and we can use an individual approach. But, if we want to create a system of service provision, a system of social help and social legislation, we need a pattern or criteria.

Finding a pattern or criteria

Generally we can find words that describe deafblindness as a disability, impairment, a condition, a handicap, and so on. We can also say that it presents pedagogical, psychological, social,

medical and rehabilitation problems. In general, it is an anthropological and ontological phenomenon that causes serious problems to the disabled person. We know it demands our attention. In brief, deafblindness is a personal, social, cultural and political challenge.

Deafblindness is a characteristic and distinct disability. It results from the consequences of dual sensory impairment. A serious impairment of both distance senses, i.e. of sight and hearing, is not, in fact, deafblindness, but it is a cause of deafblindness. Deafblindness is not a simple sum of impairment to the two distance senses. It is something quite specific that should be considered as coincidental components impacting on other factors. So perhaps it is the combination of not just hearing impairment and visual impairment but the functional relationship between hearing and sight, and a large group of personal, biological, psychological, social, pedagogical, cultural and ethical consequences of dual sensory impairment.

The question is how to express exactly the meaning of a "fuzzy" word, like deafblindness: i.e. how to design a complete description or definition of the meaning of this complicated word. Is it possible to combine all these attributes into a simple, universal, exhaustive and general pattern?

The Formula

I propose to use formal methods, an equation, to define

deafblindness as follows:

$D = f(H, V, r, Q)$, where:

- D means deafblindness.
- f means a function or sum of the components and relevant elements which are presented in parentheses.
- H means a hearing impairment. The degree of this impairment is expressed by a diagnosis, by the type and extent of the sensory loss, and by the time of its onset. When the H component is blank, then D is blank too.
- V means a visual impairment. The degree of this impairment is expressed by a diagnosis, by the type and extent of the sensory loss, and by the time of its onset. When the V component is blank, then D is blank, too.
- r means the relation between the function of hearing and vision. I have expressed it here as a kind of coefficient, which indicates the degree to which the natural capacity to compensate for loss of sight and hearing is limited or even completely absent in case of deafblindness. The value of this r coefficient could be the multiplication of the values of hearing and visual losses expressed in percentages (or any other scale). Then it is possible to find that the resulting value varies from zero to one.

For example, using this method, the combination of total deafness and total blindness is 1. When the level of hearing loss is 83% and the loss of sight is 100%, then the r coefficient is 0.83.

- Q means a group of all the consequences and circumstances of being dual sensory impaired that influence the quality of life, e.g. aspects of development and learning, education, personal habilitation and rehabilitation, employment, living, etc. To examine this area I suggest using a facet approach to establish the concept of deafblindness. This enables us to make the process flexible as it relates to the purpose of the assessment.

Perhaps, the following facets can be appointed with common agreement:

- 1 functional use of senses (of hearing, vision, touch and movement including functional use of hearing and vision in social interaction and communication).
- 2 interaction (with physical and/or nature, social, cultural environment; proximity to the environment, exploration of the environment, social interaction and communication with the environment).
- 3 communication and language (receptive and expressive communication; interpersonal, group, social communication; development of speech; communication skills in different social settings).
- 4 psychological consequences (cognitive and social development, personal development, learning, adaptation).
- 5 pedagogical consequences (education, vocational training, educational needs).
- 6 daily living skills, activities and routines of everyday life (mobility both indoors and outdoors, living, school, work and employment, leisure time, cultural activities, etc.).
- 7 need for rehabilitation.
- 8 need for technical devices for hearing and vision losses.
- 9 need for assistance (including the help of others in a number of activities).

So, defining and describing deafblindness using the Q component could be made with the help of assessment scales for each facet. The crucial problem is to create such scales that will be commonly accepted!

Including all the components

In developing this equation to explore the concept and help find a descriptor for deafblindness it is essential that all of the components are taken into consideration. When any one of the components in the definition is not present, then the resulting D section must, in turn, be blank! If it is blank it means that, in this case, we are dealing with some other disability, which is different from deafblindness.

Helping to pin point individual support

I think this formula describes deafblindness and has the capacity to bring together all its types, forms, manifestations. It should help to point to the kind of support required to meet educational and rehabilitation needs. It can be used for developmental, educational, social, sociological, demographic, etc. purposes. It can also serve deafblind people as a tool for better self-identification, for seeking and finding their identity.

Functional elements

This formula of deafblindness gives us the framework. The components H, V, r, Q are applied with regard to real life conditions. The elements that make up these components describe the situation of a disabled person. Using this model we are free to describe them with different levels of conciseness, and from different points of view. Mainly the Q component, i.e. the one that describes the variety of attributes of human life activities, offers an important opportunity for the identification of functional elements.

Flexibility is important. For instance, when considering a deafblind student and his or her communication needs, we can apply, within this Q component, some elements of educational criteria. In this way we use it to suit a variety of purposes related to service provision in the *real world* with *real people*. In addition when formulating a definition to support national laws or regulations, the format of the definition would also enable us to follow the philosophy, the intent and the structure of existing legislation, related laws and articles.

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SIGN UP NOW

CONFERENCES

**13th Dbl World Conference
August 5-10, 2003
Delta Meadowvale Hotel
Mississauga, Ontario, Canada**



"Communication is the key to opening doors world-wide"

The Programme

Your hosts, the Canadian Deafblind and Rubella Association, have a fantastic programme of events planned for August and its not too late for you to join in!

The conference theme is **"Communication is the key to opening doors world-wide"** and speakers from across the globe will be leading sessions, stimulating discussion and involving delegates in other participative events around the theme.

Keynote speaker

Stephen Lewis will be the Keynote speaker taking as his topic "The global fight against disease: the impact of quality services"

Stephen was originally a noted radio and television commentator and for the past 2 decades he has worked for the UN, as Special Representative and then as deputy Executive Director of UNICEF. In that capacity he acted as a passionate advocate for the rights and needs of children, especially those in the developing world. His work has involved him in many significant areas with impact across the world. In particular, Stephen was a member of the panel investigating genocide in Rwanda and is Kofi Annan's Special Envoy for HIV/AIDS in Africa. This year he was appointed Companion of the Order of Canada, Canada's highest honour for lifetime achievement.

Plenary speakers:

Michael Collins (USA)
Dr. Jan van Dijk (NL)
Dr. Jude Nicholas (Norway)
Craig MacLean (Canada)
Cherry Bulmer (Canada)
Joe McNulty (USA)
Jacques Souriau (France)

DBI Network meetings will take place including:

Charge Network
Communication Network
Congenital Deafblind Adults Network
Employment Network
European Usher Syndrome Network
Usher Syndrome Study Group
Nordic Culture Network
Tactile Communication Working Group
Multiple Disabled Visually Impaired Network
Research Focus Group
Rubella Focus Group
Family Focus Group

And introducing ...

Siblings network

There will be meetings of:

Annual General Meeting of CDBRA
Dbl General Assembly

There will be plenty of opportunity to get together socially, take a tourist trip and to enjoy a Banquet with the Dbl Awards with dancing afterwards!

Email: mail@dbiconferencecanada.com

Register on line: www.dbiconferencecanada.com

Telephone: 519 372 2068

Fax: (519) 372 0312

Mailing Address:
1658-4th Avenue West
Owen Sound,
Ontario, Canada

Management Committee and Council news

On the 7th and 8th March 2003, the Management Committee and Council met in London. Over the two days of meetings, many issues were discussed including details of the forthcoming World Conference in Canada, the European Conference in Slovakia in 2005 as well as the possible location of the World Conference in 2007.

If you wish to request a full copy of the minutes, please contact us at dbi@senseinternational.org.uk

We are currently looking forward to an excellent World Conference in Ontario, Canada, later this year. DbI are sponsoring 7 people to attend the Conference this August, who are all from countries with developing deafblind services including Kenya, India, Brazil, Slovakia and Croatia.

An update on the Nominations Committee

The Nominations Committee reported on their progress to date. This Committee manages the election process for a new Council and Management Committee to be appointed at the World Conference in Canada. A new Council and Management Committee will be appointed in August at the World Conference.

The General Assembly

The next meeting of the General Assembly will take place on Tuesday 5th August prior to the World Conference, in Canada. All interested persons are welcome to attend and any person may speak at the meeting although only voting members may vote. A list of voting members will be available at the meeting.

Membership Update

There are currently 585 members from 77 different countries. If you have not already done so, please renew your membership to Deafblind International (DbI) for 2003. Our membership costs involve a yearly fee based on the calendar year and it really helps the organisation if you are able to return the papers promptly. This year we intend to update our database, therefore it is very important that you renew your membership as early as possible. If we do not hear from you by September 30th, we will assume you no longer wish to be a member and your details will be removed from the database.

We are also asking you to update the information we have about you and your organisation. If you have any queries regarding your current membership or would like to complete the membership form via email, please do not hesitate to contact us on dbi@senseinternational.org.uk



Tara
Kaikini

European Conference – Slovakia 2005

The DbI European Conference in 2005 is to be held in Cervenica, Slovakia. Vice-President, William Green is on the Scientific Committee and DbI Secretary, Richard Hawkes is on the Planning Committee.

DbI Website

For the very latest news and information on DbI, visit www.deafblindinternational.org. Log on in August for instant updates on this site from the World Conference as it happens! We always welcome new submissions to the website so if you would like to contribute or advertise an event or recent success, please send details to Malcolm Matthews at mmatthe@sense.org.uk

The DbI Secretariat

If you have any DbI queries, please feel free to forward them to Tara Kaikini at the Secretariat. Tara can be contacted by email at dbi@senseinternational.org.uk or by post to: DbI Secretariat, 11 – 13 Clifton Terrace, Finsbury Park, London N4 3SR.

DbI 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 DbI through either a corporate member or an international network. Non-voting members will receive a copy of DbI Review and other relevant DbI information. Non-voting membership costs US \$30 a year or a discounted US \$100 for 4 years.

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

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

Large Corporates:

Annual Fees between US\$3,000 and US\$5,000

Small Corporates:

Annual Fees between US\$300 and US\$1,500

Corporate Members can be nominated to sit on the Council.

Non-Voting Membership

☐ I would like to join/re-join DbI as an individual non-voting member (*please delete as appropriate*)

I wish to pay an annual fee of US\$30 ☐
or £20 ☐ (payment attached)

I wish to pay for 4 years' membership at the **discounted rate** of US\$100 / £65 ☐
(payment attached)

Please waive my membership fee as I am unable to pay it at present ☐

Please debit my ☐ Visa ☐ American Express
☐ Mastercard

Expiry Date

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

Please find enclosed my Postal Order ☐

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DbI Review (tick one box in each category)

I would prefer to receive DbI Review in:

☐ English ☐ Spanish

I would prefer to receive DbI Review on:

☐ paper ☐ disk

Please return to:

Tara Kalkini, DbI,
c/o 11-13 Clifton Terrace,
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DEAFBLIND INTERNATIONAL

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Small corporates:

Annual fees between US\$300 and US\$1,500

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

We submit an annual fee of US\$ _____

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

Method of payment (must be made in US dollars)

☐ Cheque or international postal order

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Name of Bank: RABOBANK

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URGENT NOTICE: Please fax your completed form through to Ton Visser, DbI Treasurer, on +31 73 55 12 157, or post to Ton Visser, DbI Treasurer, c/o Instituut voor Doven, Theerestraat 42, 5271 GD Sint-Michielsgestel, the Netherlands.



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