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Review

Paths to Independence

Pages 4–6

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The editor will be pleased to receive articles, news items, letters, notices of books and information on forthcoming events, such as conferences and courses, concerning the education of deafblind children and young adults. 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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A MESSAGE FROM THE PRESIDENT

As we discard the old calendar and hang up a new one, it is the season for reviewing the past and making resolutions for the New Year. I have been recently reminded of several events that have caused me to believe that within Dbl we must band together to support one another. I share them for your reflection.

I remember hearing about a year ago that Michigan School for the Blind had closed its doors due to political decisions. MSB was one of the places where my wife and I had worked during our early years in deafblindness. It was not just another school for the blind, it had been, in its day, one of the leading programs in deafblind education in our country. It was a center where teachers from throughout the Midwest of America came for training in conjunction with the local university. It thrived during the 1970s, offering a program to 30-40 deafblind children, and serving as a statewide resource center. Lieke De Leuw of Holland worked there for a year, training staff

in the methods developed by Jan Van Dijk. How sad, I thought, to see a place of such expertise become extinct. I dare say that it would help Michigan services even today, in the environment of inclusion, to have such a resource.

This past Fall, Maria Inez Peterson of the Centrau program in Brazil wrote to us to explain that, in her home state, inclusion policy is being interpreted to mean that all special schools and programs must be closed. This would, in fact, mean the closure of her school. It is, of course, a serious threat to the only specialized program in this fairly remote area of Brazil. If her program were closed, deafblind children would in theory be integrated successfully into regular schools throughout the state. In practice, they would be placed in such schools, but with no specialists or knowledgeable personnel to assist the local schools to do an adequate job.

We have seen similar concerns in the Nordic countries. Not very long ago,

EDITORIAL

We have rather a mixture of articles for you this time – with no particular theme, but with some thought provoking ideas focussed around an individual's path to self expression, independence and a sense of belonging. Kiruri Kamau, writes about the challenges for deafblind people in an East African culture and describes the impact of community-based



programmes for deafblind people and their families. We are fortunate to have the

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Ekeskolan in Sweden was the major center of expertise for the education of deafblind children in the country. Today its program, too, is closed and that country is without a major center of expertise for children.

Our colleague, Ximena Serpa of Colombia, has experienced a similar problem with her program in Bogota during recent years. Because there has been no continuing government support to sustain the services, she reluctantly had to cease operations earlier this year. A program that she has personally raised from its humble beginnings, one that served dozens of children, has disappeared from the map.

opportunity to be the first to report the research that Heather Murdoch has been undertaking over the past five years into the way in which children adopt, adapt and use repetitive behaviour. She provides some valuable insights into this area of communication. And on this theme, Marion McLarty from Scotland contributes to the debate on the use of Objects of Reference and develops it with great clarity.

If you are seeking practical advice and support we have that too! You can read more

The key point here is not a message of gloom, but a call for vigilance and awareness of trends. We are reminded that our programs are sometimes fragile, and only as secure as our ability to defend them. In the case of Maria's program in Brazil, many of us have written protesting the new policies. Hopefully some of this support "from outside" can help. In the case of Sweden, the happy news is that they are considering establishing a new resource center and source of expertise for the country, fully cognizant of the need now that they have lived with such services for a while.

In our field, we work hard to establish even the most basic services. We need to commit ourselves at the local level to advocate as firmly as possible for good services to be retained and expanded. Within Dbl, we need to focus on using each other as resources when confronted with such trends in our home region. Let our New Year's resolution be to help each other, in the defense of one another's programs, as the need arises.

The happiest of New Years to all our members!

Michael Collins

about starting and equipping a light stimulation room from scratch and, in addition, you have everything you need to know to run a deafblind awareness training day with colleagues!

So thank you to all our friends around the world, who, through this magazine are willing to share their experiences! And can we join Mike in wishing you all a very happy and peaceful New Year.

Eileen

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Community-based rehabilitation of deafblind people in East Africa



Kiruri Kamau describes the way in which CBR projects are changing attitudes to deafblind people in East Africa.

John Ngamia was born deaf in 1976 near Mumias town in Kakamega district. Very soon afterwards he started losing his sight, effectively becoming a multi-handicapped person. Although he has some residual sight and therefore not totally blind, in disability parlance, John is deafblind. When he was about 10 years he joined Kabarnet School for the Deafblind, the only fully fledged school of its kind in East Africa.

After years of rehabilitation which involved teaching him the daily living skills appropriate for people like him, vocational training and basic academic skills, he moved to Sikri Agricultural Training Centre situated at Oyugis in Rachuonyo district.

When John finished his training at Sikri it was time to head back home. But there was a hitch. His family is poor with only a small piece of land where they do subsistence farming. His teachers at Sikri and those who had sponsored him decided their work was incomplete until they had set him up on his own. A

fundraiser was organised which raised over Kshs.90,000. With this money he has bought himself a parcel of land and a grade cow which has put him on the road to complete independence.

In the last twenty years, since deafblind work started in the East African region, a lot has happened which has helped not only the expansion of the work itself but a re-evaluation of the traditional way professional work among disabled people has progressed.

Deafblind children like other disability categories normally bear the brunt of superstitious customs which are endemic in African cultures. When a child is born with any form of disability, the first reaction by the family is to seek an explanation from the past. African cosmology sees disability as a result of either past sins by the parents, a curse by the ancestors or an omission, like the child being born before certain traditional rites were performed.

The result is that the child and the family are subjected to debilitating stigmatisation

which in some cases might result in ostracism by the community. Faced with such a situation the family can do a number of things. They can hide the child from the larger public from infancy to their death. There have been known cases of children being tethered like animals inside the house to hide them from public glare, or in extreme cases some parents even resort to infanticide. Where institutional facilities exist the child is dumped there and forgotten completely.

Missionaries who pioneered work among the disabled in this region found they had little choice but to take in the children brought to them and keep them in institutions as long as they could afford it. The effect of this was that these children were dislocated from their communities, completely institutionalised and in adulthood their absolute dependency on strangers made them strangers in their own homes.

The new approach to the rehabilitation of the disabled, known as community-based rehabilitation, has been to move away from



Sylvester Cherviyot of Kabarnet School for Deafblind learning carpentry. Sylvester will proceed next year to vocational training.

institutionalisation and dependency towards making individuals more independent within their own cultural communities. The work towards this goal, which has been going on among the deafblind in East Africa, was the result of observation and evaluation of what had been done in the past. Two approaches were considered.

The first option was considered at the Kabarnet School for the Deafblind, the first such institution in the East African region, which is situated in the Rift Valley region of Kenya. As work progressed in the 1980s a new challenge presented itself. The first children in the school were becoming adults and there were no programmes in place into which they would be absorbed once they had finished their academic and vocational training. What

was going to happen to them? Were they going to stay at the school all their lives?

It was decided, bearing in mind the negative attitude towards the severely handicapped by the society, that a programme, based on the Swedish approach of group homes for the disabled, be started at the school. The essential features of a group home include people with similar disabilities living together while their vocational aptitudes are assessed. From the results of the assessment, diverse income-generating activities are started and each individual is given a chance of being gainfully employed while still living within a community that understands and accepts him or her.

When all the facts were on the table the idea was discarded. The cost of

starting a group home, it was noted, would be prohibitive in a country with limited social welfare funding by the government. It would also mean the donors would have to support such a programme forever.

African cosmology sees disability as a result of either past sins by the parents, a curse by the ancestors or an omission, like the child being born before certain traditional rites were performed.

Secondly, and most importantly, such a programme would defeat the very idea of rehabilitation which should aim at making the disabled independent and socially integrated after gaining the necessary skills. The case of Ruth Wambui



Mrs Mary Kimani of the Nairobi Deafblind Unit with her daughter, Shiku Kimani, a pupil at the Unit.

graphically illustrates the tragedy of institutionalisation.

Ruth left home when she was a very small girl to go to a deaf school. In traditional African society, deafness is not seen just as a disability but is equated with stupidity because deaf people cannot effectively communicate with other people.

Apart from removing the stigma from the family, Ruth was happy to join others, like her, with whom she could communicate and at the same time gain some useful skills.

After completing school she was employed as a house mother in a deaf school, got married and had children. Then, just when everything looked so rosy, tragedy struck. Ruth was involved in a road accident that took away her sight thus

effectively leaving her deafblind. As if that was not enough her husband left her with all the children to take care of. Finally she lost her job as a housemother.

It was at this point she decided to go back to her rural home in Muranga in Central Kenya. To her dismay she found herself a complete stranger not only to the community she left as a child but even to her own brothers and sisters. Though now she has been rehabilitated as a deafblind person she still has problems relating to her own people, whom she has been forced to return to due to her deafblindness.

It was at this point that the idea of community-based rehabilitation was considered. The idea of community-based rehabilitation presented an enormous challenge not least because very few parents of deafblind children were involved in their children's welfare. Some were just happy to pass on the burden to an institution and literally dump their children there. In the second instance, and this was welcome because it provided opportunities to educate, this approach would involve the challenge of disabusing both



Milka Akego, a student at Kabarnet School for the Deafblind

parents and the communities of their superstitious beliefs and impressing on them that the disabled are no less human than those who are not and that the responsibility of rehabilitation is the burden of not just the immediate family but also the larger community.

The experiences of the last few years have vindicated the choice of community-based rehabilitation and now more and more effort is being expended to expand the work further through concerted awareness building especially directed to parents, community and opinion leaders.



Penny May Kamau talking to Wilson Masinza

Repetitive behaviours in children with sensory impairments and multiple disabilities



Heather Murdoch

Many children with sensory impairments and multiple disabilities show repetitive or stereotyped behaviours – for example, rocking, head shaking, mouthing objects or repeating sounds. Those working with the children may be unsure how best to respond, particularly when programmes emphasise communication but the child's behaviours appear self-directed. Heather Murdoch recently completed her PhD thesis at the University of Birmingham on this topic, looking at the roles which repetitive behaviours may play in children's development and the ways in which educators interpret and respond to them.

Repetitive behaviours are very common in children with multiple disabilities and sensory impairments, and in some cases dominate the child's choice of activities. Expert advice on how to respond has differed over time: from using behavioural techniques to reduce the behaviours, to finding activities which the child finds more interesting (often a difficult task), to addressing the development of communication skills in the belief that repetitive behaviours will reduce as the child's communication improves, to imitating and extending the behaviours themselves as a means of developing interaction. Current wisdom suggests that each of these approaches has a place, and that the 'best' approach will vary from child to child and

from behaviour to behaviour. In a sense, however, this leaves educators no better off, unless the expertise and resources needed to evaluate which approach is best are readily available.

Children with sensory impairments have long been known to show *functionally equivalent* behaviours – in other words, achieving a recognised end by unusual means. Blind children, for example, often become still when listening, instead of looking towards the source of sound; children with poor peripheral vision may swing their heads from side to side when walking in order to scan the environment. Many of these behaviours are highly repetitive. The concept of functionally equivalent behaviour has been extended by Anne Nafstad and Inger Rødbrøe in their book *Co-*

My research was motivated by an interest in repetitive behaviours from a developmental perspective, and by the lack of guidance currently available to educators on this topic.

Creating Communication: they suggest that developmentally significant sequences of activities, not just individual behaviours, may be replaced by functionally equivalent actions. This suggests a new interpretation of repetitive behaviours: as an essential part of a child's development. This idea is generally accepted for nondisabled children – all babies show repetitive behaviours, peaking at around 6-12 months of age, and Piaget identifies actions performed repeatedly on the child's own body or on objects as part of the sensorimotor stages of development (*primary* and *secondary circular reactions* respectively). For children whose development is delayed for any reason, these stages (unsurprisingly) start later and last longer. For

children with sensory impairments, in addition, functionally equivalent actions may make it harder to interpret behaviour.

This is not to say, by any means, that the 'old' identification of repetitive behaviours as stereotyped actions reinforcing the child's isolation is always wrong – just that many repetitive behaviours, especially in children with sensory impairments and multiple disabilities, are more complex, and potentially of more value in development, than we used to think.

My research was motivated by an interest in repetitive behaviours from a developmental perspective, and by the lack of guidance currently available to educators on this topic. The aim of the study was to gain a clearer picture of how children use repetitive behaviours in educational settings, and how educators perceive and respond to the behaviours. Three aspects were identified for research:

- relationships between the performance of repetitive behaviours and the characteristics of sensory impairments and multiple disabilities;
- the development of repetitive behaviours over time in children with sensory impairments and multiple disabilities;
- the ways in which adults working with these children perceive and respond to repetitive behaviours.

The study was divided into three sections, one for each aspect, and the findings in each case were interpreted from a developmental perspective, focusing on children's changing abilities to interact with the physical and social environment.

Because of the dependence of children with sensory impairments and multiple disabilities on mediation (usually from adults) to access and interpret the environment, the social dimension of learning was emphasised throughout the study.

The first part of the study investigated possible relationships between the characteristics of sensory impairments and multiple disabilities and children's performance of repetitive behaviours. Past studies have found that sensory impairments (especially visual impairments) increase the likelihood of repetitive behaviours, with deafblindness and multiple disabilities associated with their persistence over time. Most studies of children with single sensory impairments, however, have not considered those with

Repetitive behaviours listed in the survey:

mouthing objects	repetitive vocalisations	hand, thumb or finger sucking	repetitive rubbing or wiping
eye poking	head movements	strobing light with hand	movements
light gazing	hair twisting or pulling	complex hand or finger movements	body rocking
sniffing or smelling	arm waving	throwing objects	bouncing or jumping
screaming	clapping	repetitive manipulation of objects	twirling
crying or whimpering	hand flapping		foot kicking
tooth grinding			

multiple disabilities, and studies of children with deafblindness have largely focused on those with congenital rubella syndrome – now barely found among the school-age population in the UK and many other countries.

In the current study, specialist teachers working with children with sensory impairments and multiple disabilities were asked to

complete questionnaires about children who showed repetitive behaviours. They were given a list of 23 behaviours (see below) and asked to record how often, for how long and in which circumstances each behaviour occurred; they could also add other behaviours. The list of behaviours was compiled from previous studies and in consultation with a group of experienced specialist teachers. Only non-injurious behaviours were considered (with the exception of eye-poking), because, if a behaviour causes injury, a developmental approach may need to be overridden by interventions to safeguard the individual. In addition, those completing questionnaires were asked for information about the child's disabilities and their effects on interaction with others and with the physical

environment. 170 completed questionnaires were returned, of which 153 could be analysed.

Very few responses (less than 10%) concerned children with hearing impairments and multiple disabilities, but full vision. In line with the findings of previous studies, this suggests that children with visual and dual sensory impairments are more likely to show repetitive behaviours

than children with hearing impairments, whether or not the latter have additional disabilities. Of the children with hearing or dual-sensory losses who were reported to show repetitive behaviours, however, those whose hearing levels fluctuated tended to show more repetitive behaviour than those whose hearing losses

Sight is a 'foreground' sense, allowing us to choose the space and level of detail viewed

were stable. This occurred whether the fluctuation was innate (for example, due to conductive or mixed hearing loss) or environmental (for example, due to wearing hearing aids intermittently). Fluctuating visual impairments, and the intermittent wearing of spectacles, had no effect on rates of behaviour.

These findings may be explained by the different roles of sight and hearing in our interaction with the environment. Sight is a 'foreground' sense, allowing us to choose the space and level of detail viewed, whilst hearing (operational even in sleep) maintains a 'background' role in alerting us to change. Studies of infants with hearing or visual impairments suggest that visual loss has a greater impact on early interaction, with people or objects, than hearing impairment. Children with visual impairments are less easily able to initiate, control or respond to interactions.

Hearing, in contrast, alerts us to change, allowing us to predict and act to control events around us. Fluctuating

hearing levels may affect the ability to identify changes, and hence the ability to predict and control. Predictability and control may be the common factors relating global visual impairment and fluctuating hearing impairment: for children unable to predict events, or to access feedback from their own or others' actions, the immediacy and accessibility of feedback from repetitive behaviour, and the ability to control its occurrence and results, may explain its increased performance. Degree of sensory impairment did not affect rates of behaviour in the current study, except in that fewer different behaviours were recorded for children with profound hearing losses. This may be because fluctuations in hearing levels cause less variation in environmental information for those with profound hearing losses than for those with milder impairments.

The explanation above fits the results of the current study, but requires further investigation before it can be accepted – in particular, of the confounding effects of dual sensory impairment and the range of strategies used by people with deafblindness to identify changes in the environment (cutaneous perception of changes in air pressure, for example).

Factors affecting the performance of specific behaviours were also examined. Children with mild-moderate visual impairments, for example, were more likely to wave than those with more profound losses; those with severe visual impairments were more likely to light gaze. Children whose hearing fluctuated were more likely to mouth objects, rock or suck their thumb or fingers. These and the other distinctions

Children who self-injured, were aggressive or showed socially unacceptable behaviours were reported to show more repetitive behaviour

found can plausibly be explained in terms of available sensory feedback, or as responses to limited predictability and control of events.

Children who self-injured, were aggressive or showed socially unacceptable behaviours were reported to show more repetitive behaviour. Although, in the current study, only non-injurious repetitive behaviours were considered, stereotypy and self-injury are very frequently performed together, and there is an urgent need for more research looking at these two types of behaviour.

The second part of the study investigated changes in repetitive behaviours over time. Three case studies of pre-school children attending a specialist Early Years Centre were carried out over the course of a year. Two of the children were deafblind and the third had a visual impairment and multiple disabilities.

Hearing (operational even in sleep) maintains a 'background' role in alerting us to change

Monthly visits were made to the Centre: on each visit, the children were observed and videotaped during their normal activities, each child's keyworker was interviewed and school records were used to give information on developmental progress or regression. The lists of behaviours developed for the first part of the study were used to gain an initial picture of each child's behaviour; then individualised lists were drawn up and amended after each visit. The keyworkers estimated the frequency, duration and circumstances of

each behaviour each month and these were discussed, together with any changes in the use or interpretation of the behaviours and any significant events in the child's life (for example, illness).

Each child showed some behaviours which varied little in frequency, duration or circumstances throughout the study.

After nine visits, the information was collated and examined. Changes in the performance of behaviours were graphed and evaluated in the light of contemporaneous changes in sensory function, developmental stage, health and other circumstances. Progressive changes in the frequency and duration of some behaviours were clearly identifiable for all three children, as were changes in the use of behaviours. One child, for example, often explored his keyworker's face and hair with his fingers. During the course of the study, he began to use speech to communicate, and this change was accompanied by more focused tactile exploration of the keyworker's mouth. Another child held objects at arm's length and tapped them; at the start of the study, he never looked at the objects when tapping. During the study, his visual function improved, and he began to show more visual curiosity; at the same time, he began fleetingly to glance at the objects he tapped, and by the end of the study he looked at tapped objects approximately 50% of the time. As he had cortical visual impairment, it is plausible that moving

objects were easier for him to see than stationary ones, but further investigation would be needed to test whether this was the case.

Each child showed some behaviours which varied little in frequency, duration or circumstances throughout the study. In addition, one child (whose health was very variable) showed some behaviours which varied over time with no apparent pattern. The first child's consistently-performed behaviours were used in interaction with his keyworker, often for turn-taking games (for example, *bouncing or jumping, tickling arm or leg, tapping surfaces in rhythm*). Most of the second child's consistent behaviours were schemes with objects (for example, *mouthng objects, dropping objects and looking after them*), interpreted as self-occupation or interactive behaviours. These two groups of behaviours appeared to be developmentally adaptive behaviours used for communication or exploration – functionally equivalent to strategies used by nondisabled children, and in this sense compensating for the restrictions imposed on environmental interaction by the children's disabilities.

One child, for example, often explored his keyworker's face and hair with his fingers.

In contrast, the variable behaviours and a few of the consistent behaviours of the second child appeared to give sensory feedback without involving another person (for example, *light gazing, rubbing head with body swaying, rocking*), whilst for the third

child, behaviours showing consistent frequency and duration generally involved non-auditory, non-visual behaviours using his own body (for example, *rubbing ear, tooth grinding, thumb sucking*). These were interpreted as providing predictability amid the inconsistency caused by his fluctuating visual and auditory function and epilepsy. These groups of behaviours showed many of the characteristics of stereotypy – self-directedness, persistence, unresponsiveness to changes in the external environment and the generation of sensory feedback. Although most models of stereotypy suggest development only in the direction of more intensely stereotyped behaviour, the evaluation of behavioural change in the current study included change in the opposite direction, with apparently stereotyped behaviours becoming used in communication or exploration as children's abilities to interact with the environment improved (with, for example, improved sensory function enabling a child to scan the environment visually).

The third part of the study investigated staff perceptions and interpretations of repetitive behaviour. Two groups of specialist teachers (eight in the first group, five in the second) were interviewed and asked how they understood repetitive behaviours, why they thought some children showed these behaviours, how they felt about the behaviours and how they would respond. The interviews were taped, transcribed and analysed to identify sections addressing similar concepts, and themes which linked different sections.

Some of the interviewees saw repetitive behaviour as something that they did, providing common ground with the children with whom they worked ...

Five themes were identified. The first concerned repetitive behaviours as a source of similarity or difference between teacher and pupil: some of the interviewees saw repetitive behaviour as something that they did, providing common ground with the children with whom they worked, whilst others saw repetitive behaviour as tied to disability and emphasising the difference between themselves and their pupils. The second theme was that of obstruction: repetitive behaviour was felt by some teachers to interfere with the child's learning, with their own teaching and/or with teacher-child interaction. Some saw interference with learning and with teaching as virtually indistinguishable, whilst others felt that the child should lead the teacher in teaching, and that the idea of repetitive behaviours interfering with this process was therefore inappropriate. The third theme concerned teachers' understanding of pupils, with the identification of potential functions of repetitive behaviour. The functions identified fitted with the accepted theories of deafblindness and its implications for development, and often also with accepted models of stereotyping. The fourth theme concerned decisions about action from the teacher – judgements about whether and how to intervene – and the fifth theme identified repetitive behaviours as powerful, with some interviewees speaking of them almost as if they had

a life of their own. Some of the themes (the first and fifth) dealt with emotional responses to the behaviours, whilst others (the third and fourth) were cognitively-based. This part of the study was a very small-scale, preliminary enquiry, but the results (especially the range of responses) suggest that further research is warranted, and would assist those developing guidance for teachers in this area: the ways in which teachers currently perceive repetitive behaviours are an essential consideration.

Overall, the study findings suggested that the repetitive behaviours of children with sensory impairments and multiple disabilities comprise at least three categories: self-directed, stereotypical behaviours; delayed, developmentally normal behaviours, and functionally equivalent behaviours compensating for the effects of sensory impairments. Although these categories could each be identified in the literature, they had not been brought together before, and empirical evidence for their existence was sketchy at best. Neither had the idea of movement between categories previously been explored in detail.

All the study participants wanted to change children's behaviours in some way, either directly or by appropriating existing behaviours for new (usually communicative) functions. The purpose of education, and the *raison d'être* of

... whilst others saw repetitive behaviour as tied to disability and emphasising the difference between themselves and their pupils.

teachers, can be understood as the engendering of change in children's understanding and behaviour.

For this reason, there is a need to make explicit the factors affecting children's performance of repetitive behaviours in educational settings, and teachers' responses to the behaviours. The use of a developmental framework in studying this topic seemed appropriate, and potentially the most helpful approach for educators. Further work is needed on the use of repetitive behaviours in developmental, interactive teaching approaches, and it is hoped that the information from this study is useful both to those working directly with the children, and to those engaged in research and training.

Further information about the study is available from Heather Murdoch, who can be contacted c/o the Editor, Dbl Review, Sense, 11-13 Clifton Terrace, London N4 3SR, UK.

Developing a Sensory Stimulation Room

Vimal Thawani from the Blind People's Association, Ahmedabad, India discusses the design process in the development of this new resource, and its uses.

I came back with a number of ideas and a great deal of enthusiasm to develop something on similar lines



The white room, the dark room, the light room, and the stimulation room! These were the various names I heard during my visit to different schools for deafblind and multi-sensory-impaired children in the UK. I kept wondering what this room would look like and what its function would be? I visited three different schools and all three schools had such a room but each had a different name! I observed the children using the rooms, discussed it with teachers concerned and the Headteacher and tried to understand the way in which these rooms could be used. This was my first experience of understanding and interacting with deafblind children.

I came back to India with a number of ideas and a great deal of enthusiasm to develop something on similar lines but, of course, suited to the needs of Indian conditions. I discussed my plan with my Executive Director and my colleagues. By good fortune, at this point the National Institute of Design (NID), Ahmedabad approached BPA to suggest a design project. The BPA team discussed their initial ideas and convinced them to take up an innovative and challenging project like this. At the outset the NID team experienced an orientation programme in deafblindness

SENSORY STIMULATION ROOM

and then began joint-working with BPA on the physical design of the room.

We studied the needs of deafblind/MSI children, listed "musts" in the room and tried to dovetail this with basic design strategies. The following emerged as objectives for its use:

Assessment – Clinical and functional aspects

- Sensory stimulation of children with multi-sensory impairments
- Sensory training in the use of residual abilities
- Interaction with immediate environment

Communication skills – development

- Relaxation
- Equipment and lights to facilitate communication.

Today we have:

- strobes, flasher lights, spot lights, mirror balls, focus light and u.v. lights to measure tracking, fixating and use of vision
- an optic fibre corner and visual motor corner
- resonance board, stimulation box, vibrators
- some devices of different frequencies and intensities
- tactually stimulating surfaces of different qualities
- suspended objects from different surfaces, lengths and textures

By offering the child the opportunity to explore with his touch senses and enjoy the activities in the room we hope ultimately it will encourage him to understand and develop communication with his environment.



With the help of the different areas in the new resource children learn to use their residual vision more effectively



Our experiences last year

Our experience of working with children and of the use of the stimulation room has been very encouraging. The room has evoked several surprising responses, including curiosity and interest from deafblind people and their families as well as the professionals. It

has been of great help in the following ways.

Assessment:

Most of DB/MSI children visit medical professionals and come back with notes "Child uncooperative ... Totally blind ... No vision ... unable to assess ..."

The Stimulation Room has been used for functional visual assessment and we have been able to help the child to understand the use of his residual vision. For example, Daya, a 3 year old, deafblind girl came with a diagnosis of 100% visual loss. Today she has learned to use her residual vision more effectively and is able to focus on objects. She has developed "object permanence" ability to some extent. With the help of focus lights and the mirror ball

movement, the child has learnt to fixate her gaze, track the object or light and follow it.

For most of the children the room has been of immense help in doing visual, auditory and tactile functional assessment. This, in turn, has helped in developing a needs-based individual education programme.

Communication:

We have developed a lot of our own materials like flashcards with fluorescent colours for story telling. We have used the low cost materials which glow in ultra violet light. Thus, through turn taking games and story telling through fluorescent cards and tactile objects, the child is encouraged to interact with the teacher and the environment. The stimulation box helps the child to get oriented with the objects of day-to-day use and the child learns to understand the environment more closely.

Relaxation:

A number of children find this room very comfortable and cosy and they enjoy and develop associations with particular music or sounds combined with the lights of their choice. We have used it a lot for hyperactive children to help them to calm down. In the case of some children this room is used as a reward.

Conclusion

As you can see the Sensory Stimulation room has helped a lot and supports our work with children particularly in the areas of communication through the use and integration of different sensory information as well as conceptual development.



For most of the children the room has been of immense help



The Stimulation Room has been used for functional visual assessment and we have been able to help the child to understand the use of his residual vision.

Practical deafblind awareness training: simulation exercises

Sharon Barrey Grassick from Western Australia, discusses some effective approaches to training.

Hands-on activities simulating a combined hearing and vision loss are an excellent way to start any deafblind training program, to provide an acute awareness of the unique disability of deafblindness.

Feedback regarding the type of training described below certainly indicates that simulation of both hearing and vision loss is one of the most practical and powerful strategies for allowing participants to experience, if only for a few minutes, what it *might* be like for a person to be deafblind.

But, before you start the simulation activities, advise participants that no matter how much simulation they do, they will never really know what it is like to be deafblind 24 hours a day, 365 days a year. The following experience will at least give participants some idea of the impact of deafblindness, and will certainly provide them with something to think about.

You might even think that some of what follows sounds harsh or unrealistic; but the exercises really make hearing-sighted people working with individuals who are deafblind stop and think. What kinds of messages are we really giving? How are we making deafblind children feel? How are they interpreting what we do, or neglect to do?

The examples are all things that are happening out there - in schools, homes and

residential settings - and happening far too often! Frequently these actions are performed by very well-intentioned people who genuinely care about the children, but who are simply not aware of how their actions, or lack of appropriate actions, may adversely effect an individual.

Setting up

Arrange chairs at the front of the room for the 'deafblind' volunteers. The number of chairs will depend upon the size of the group, but 4 or 5 chairs is a workable number. At least one chair should be on wheels or castors, and chairs should be placed far enough apart to allow for a person to walk between them.

Arrange for a whiteboard and markers, or similar, for writing comments following the participants' experiences.

Generally, start with 4 or 5 volunteers at a time blindfolded or wearing simulation goggles and ear plugs. Simulation goggles can be made from bubble wrap cut in the shape of a blindfold with string attached at the sides for tying behind head, or by taping the bubble wrap over inexpensive swimming goggles. In the absence of ear plugs, simply request that there be no talking or auditory cues while doing the activities.

Try to allow time for every participant to have a turn at being 'deafblind'.

Try to allow time for every participant to have a turn at being 'deafblind'.

Group 1

Ask for 4 or 5 volunteers to sit at the front of the room. Once blindfolds are in place, gesture for different members of the audience to come up, one at a time, to do one of the following actions with one person in the group who is 'deafblind'.

Blindfolded volunteers are to be given no warning as to what will happen. The different actions can be written on slips of paper to eliminate the need for any verbal cues to the audience. Choose 'victims' randomly, so that the volunteers in the group cannot anticipate who will be next. The person from the audience who performs the actions below is to return to their seat when finished.

Remember, no physical or auditory cues are to be given as to what will happen.

- Give no warning and put cup (plastic) of water to lips of person number 2 to take a drink
- Give no warning and take off number 5's shoes
- Give no warning and pull number 3 from chair, take a few steps, then leave standing with nothing to hold onto and nowhere to sit
- Give no warning and brush number 4's hair
- Give no warning and ruffle hair of person number 1

When the previous actions are finished, say nothing ... just leave the group of volunteers sitting blindfolded, with no one speaking for about a minute. Then tell the group to take off the blindfolds and one by one ask how they felt. Write their comments on a whiteboard or overhead. Ask if

SIMULATION EXERCISES

they had any idea who it was in the room that interacted with them while they were blindfolded. Talk about any body language of those who were blindfolded that was observed by people in the audience.

Group 2

Ask for 4 or 5 different volunteers from the audience. As soon as they put on blindfolds, make sure no one in the audience speaks or gives any auditory clues. Do nothing for about one minute in complete silence, then have all of audience stand up and walk around, moving chairs, picking up and putting down cups, books, etc., and generally making everyday noises. Stop and have silence again for another minute. Then start moving again, this time gently moving past legs and brushing against chairs of 'deafblind' group. Return to chairs in the audience, and wait in silence for another minute. Then tell group to take off blindfolds and one by one ask them to share their feelings. Write their comments on a whiteboard or overhead.

Group 3

Ask for 4 or 5 different volunteers from the audience. Make sure there is a chair on castors for one of them. When blindfolds or goggles are in place, gesture for different members of the audience to come up to the front to do one of the following actions to one of the volunteers.

Again with no warning:

- Pull person 'b' from chair and take to another chair across room
- Put cookie to mouth of person 'd' to eat
- Take off (or put on) sweater or jacket of person 'a'
- Rub different unusual textures on hands of person 'c'
- Push (from behind) person 'e' sitting in chair with wheels a few steps, stop, push again, stop.
- Then ask group to take off blindfolds and one by one ask how they felt. Write their comments on a whiteboard or overhead. Ask if they had any idea who it was in the room that interacted with them while they were blindfolded.

Pictures from a staff training session that was conducted at the Royal WA Institute for the Blind in Perth, Australia.



Choose 'victims' randomly, so that the volunteers in the group cannot anticipate who will be next.

Group 4

After the next group of volunteers are blindfolded, silently indicate to the entire audience to leave the room, making only a minimal amount of noise in doing so. Have the audience wait in a corridor or outside for 2 full minutes, with no-one in room with group. Have only one person go back into the room and tell the group to take off blindfolds, then the rest of audience can come back into room, while participants make comments on how they felt.

Feedback

It is almost guaranteed that you will get at least some of the following comments from those who were blindfolded, and observations from those in the audience:

feeling of isolation; lack of control; lack of choice; apprehension; fear; lack of respect; meaningless; passive cooperation; anxiety; curiosity; boredom; on edge; powerlessness; need to

completely trust others; anxiousness; would it happen again, or was it finished; disappointment; withdrawing; shutting out; thinking something was about to happen but not knowing who, what, when, where or why; tension; anticipation.

Food for Thought

Advise audience of the following points:

- Participants have already seen the environment before being blindfolded; therefore, visual memory would be an advantage.
- Participants have already seen other participants, and probably some familiar friendly faces, upon entering the room.
- Participants have already heard familiar voices of people and environmental sounds before simulation activities commenced.
- Participants already have speech, language and communication skills - compare this to a person who has never heard speech clearly or seen lips or facial expression clearly.
- Participants have spatial awareness and have learned to put things into context.
- Participants all knew that they wouldn't be hurt, and that it was only for a few minutes.



Regardless of all of the above points, remind participants that they still listed the above feelings. So just imagine how someone who is deafblind feels when people do not let them know who they are, what is about to happen, where they are going, and why something is about to happen. There is a simple but structured way this can be done, as follows:

Approach and Making Contact

Demonstrate an appropriate way to approach and make contact with a person who is deafblind. (CUEmunication hand-out can be used.)

Approach from front to give opportunity to use any residual vision. Do this before any physical contact is made. Say child's name as you approach, and your name, to give opportunity to use any residual hearing.

Do this before any physical contact is made. (Note: even if there is limited hearing, the one word a child may have heard more than any other would be his name, so he may respond to that before any other word. Also, if he is able to hear it, saying his name first alerts him that the person is coming to see him.)

Place your hand on the back of the child's hand and wait for the child to respond in some way.

Then sign hello by moving your open palm in a circular motion on the back of his hand. If he offers his palm, you can sign on his palm. If the child is at the stage of using a tactile name sign, do so, and give your name sign as well, eg. 'Hi John, it's Sharon here.'

Then identify yourself by offering your hand under his to feel some piece of jewellery that is always worn, eg. wedding ring, watch. Do not take child's hand and rub on jewellery. Allow child to locate it by offering it under his hand. (Note: if no jewellery is worn, simply offer hand.) Proceed with child's preferred communication system so he can anticipate what will happen next, eg. touch cues, object-symbols or tactile signs.

Demonstrate basic sighted guiding.

Ideally, at this stage of the training, participants should have an opportunity to again don blindfolds and do the simulated exercises again, but this time to practice the approach outlined above, guiding appropriately where required and providing information in a meaningful and non-threatening manner. Stress the importance of consistency.

Some suggestions follow:

- 'Approach', give empty cup

Demonstrate an appropriate way to approach and make contact with a person who is deafblind.

and indicate to stand up; guide to table where drink is.

- 'Approach', tap chair, offer arm, guide to another chair, indicate where chair is.
- 'Approach', give cup, gently tap side of mouth, allow person to bring cup to mouth.
- 'Approach', give biscuit, gently tap side of mouth, allow person to bring biscuit to mouth.
- 'Approach', offer variety of textures.
- 'Approach', give brush, touch head, guide hand to brush hair.
- 'Approach', tap shoes, guide person's hand to assist in removing shoes.

In conclusion

A common response to always letting the student know who you are, including identifying yourself again even if you're only away for a few minutes is, "But I'm sure he knows who I am." Make reference to all of the adults who are likely to have contact with him during any given day - teachers, education assistants, principal, speech therapist, physio, OT, music specialist, swimming teacher, bus aide, volunteers, students, nurses, visiting teachers, etc. Then ask how can they be sure?

Another comment in regard to approaching in a consistent and structured manner is, "But, I just don't have time." Ask for someone to use their second hand to time you, and demonstrate the approach (it generally takes about 6 seconds).

Use video clips to demonstrate appropriate approach and communication.

ASSUME NOTHING -

Deafblindness: an Introduction, available from the WA Deafblind Association, has some good examples.

Whose communication is it?

Marion McLarty of the University of Strathclyde, Scotland develops the continuing debate on how we use Objects of Reference effectively in communication strategies.



Marion McLarty

Introduction

The use of Objects of Reference to support the development of communication and understanding has been established practice in the education of deafblind and multi-sensory impaired children and young people. In recent years, use of this type of augmentative communication has spread to those engaged in the education and support of pupils/students/clients with profound and multiple difficulties. Unfortunately, evidence indicates that this is not accompanied by an increase in real understanding of the methods and that, even for those engaged in deafblind education, a level of confusion exists among practitioners.

The use of Objects of Reference to support the development of communication and understanding has been established practice in the education of deafblind and multi-sensory impaired children and young people.

This confusion may be attributed, to some extent, to the relatively limited range of written information available to those who wish to develop this approach. While authors such as Park (1995) and Rowland and Schweigart (2000) publish informative, research-based articles in academic journals, most practitioners, (teachers, care-

workers, social tutors) are more likely to turn to the more accessible 'how-to' type of publication provided by Ockleford (1992).

Practitioners, often short of time, pressurised by demands of national curricula, set timetables and other external factors are also often impatient and even distrustful of what they see as 'theory'; their concern is with practice. This creates a tendency to demand a quick 'recipe' which is then applied to their own working situation. That this is an inadequate response to the challenge to develop real understanding and communication with deafblind learners is generally agreed by professionals from a number of countries.

Human rights and self-determination

This factor, which can no longer be ignored, has become central to our thinking and planning over the last five years. This must necessarily impact on the way we relate to deafblind people in all areas of their lives and, most particularly I would argue, in the area of communication.

The challenge to society which was articulated twenty five years ago that, "Disabled people are ... an oppressed group in society." (UPIAS and Disability Alliance, 1975, p14) is still, unfortunately highly relevant today. Some might argue, that while this statement might have validity

when applied to the experience of those who are 'only' physically or sensory disabled, such an argument has little to do with those with pronounced and multiple disabilities who are highly dependent on others for their very survival. Clearly, to argue for increased independence in its everyday sense, for such individuals, cannot be regarded as being in their best interest. However, if we are beginning to listen to those who are able to speak for themselves then principles of justice and equality demand that we consider the rights of all those with disabilities.

The dependency experienced by individuals with severe impairments might be regarded as similar to that which an able-bodied person might experience on the occasion of serious illness. At such a time, most people are content to surrender responsibility and independence to 'experts' who, they hope, will know the best course to return them to complete fitness, at which time they may resume full power and independence over their own life. This being the case, it has long been accepted that the supremacy of those in the medical and caring professions over every aspect of the lives of physically dependent adults was a proper response to their impaired faculties. This limited view is slowly changing, a process given greater impetus by highly publicised instances of well above-average intellectual ability on the part of

individuals with massive physical impairments. The results of the clearly unimpaired intellectual powers of Steven Hawking, communicated by way of highly sophisticated technology are important to those working in his academic field but have also played a vital part in the raising of public awareness. He has demonstrated that, in spite of total physical dependence he is still much more intellectually able than most of his carers and, indeed, than most of the population.

The story of Jean-Dominique Bauby, told in the best seller, *The Diving-Bell & The Butterfly*, is another instance of public recognition of great intellectual ability combined with total physical disability and perhaps something more. We read that, "After suffering a massive stroke, ... editor-in-chief of French *Elle* and the father of two young children, found himself completely paralysed, speechless and only able to move one eyelid. With his eyelid he 'dictated' this remarkable book". (Bauby, J.D. 1998, backpage)

It is clear, however, when reading the account of his experience that his story might never have reached the public but for the actions of one member of hospital staff who demonstrated an unusual measure of awareness and intuition.

"The identity badge pinned to Sandrine's white tunic says 'Speech Therapist', but it should read 'Guardian Angel'. She is the one who set up the communication code without which I would be cut off from the world. But alas! While most of my friends have adopted the system, here at the hospital only Sandrine and a female psychologist use it (Ibid.p47)

Bauby's limited control of his life was dependent on Sandrine's system and on those who would consent to use it; his only avenue of influence was communication. The similarities between his situation and that of many deafblind people cannot be ignored.

Social justice and effective practice

If we are concerned with human rights, dignity and self-determination it is clear that we must necessarily be concerned with the effectiveness of systems of communication. We must ensure that we are not merely going through a meaningless exercise in order to please some higher authority. If we see ourselves as being accountable, first and foremost, to deafblind pupils/students/clients then we must carefully consider the system of communication used and be willing to evaluate its effectiveness. There are a range of communication options which could be greatly improved through rigorous re-evaluation but, as the focus of this article is Objects of Reference this is the only area which will be discussed. It has already been remarked (McLarty, 1994 & 1997) that there is a worrying tendency on the part of many practitioners to regard the objects themselves as containing some inbuilt communicative properties while largely disregarding the importance of personal experience, environment and context. It is useful then to ask some basic questions to guide our thinking when considering the way we communicate with congenitally deafblind and multi-sensory impaired people.

Whose communication is it?

Most of us have many modes of communication; deafblind people have a much more limited choice. The system of augmentative or alternative communication chosen should not be seen as belonging to professionals or establishments, rather it should be clearly recognised as belonging to the deafblind person. It must therefore be that which is most suited to the person who will be dependent on it for understanding and any level of self-determination.

What is the stage of development of the deafblind person?

Irrespective of our convenience, is the person able to access the method? Do they understand the concept of symbolisation? What can they see? What can they hear? How much are they likely to understand through tactile methods?

What is meaningful to the person?

How much do we know about the experiences of the person with whom we are working? Can we be sure that what seems meaningful and important to us is equally meaningful to them. It can be seen clearly in these three questions that what is advocated is a person-centred approach. This may be seen as problematic for establishments, schools or services, but nevertheless, in order to be valid and effective any approach to augmentative or alternative communication with multiply disabled people must be individualised. In order to support practitioners who wish to employ this individualised approach to the use of objects of reference rather than a depersonalised, 'recipe' approach, the following process is suggested.

We must ensure that we are not merely going through a meaningless exercise in order to please some higher authority.

Objects of reference: practical starting points

Information gathering:

a clear and detailed picture of the individual is required. This will involve data from a range of sources; medical assessments of sensory and physical functioning and health issues; educational assessments regarding likely levels of understanding and concept development; family, friends and previous staff who have vital information on personal experiences, preferences and interests and last, but certainly not least, practitioners' observations in all these areas. Objects of reference should always be used according to individual needs and never because another member of the class or group is using the method.

Preparation:

the starting point will be dictated by the person who will use the Objects of Reference. Many will have a level of visual functioning and concept development which will allow them to make good use of miniaturised, two-dimensional or otherwise more symbolic objects. If this is the case it would obviously be greatly damaging to morale and motivation to start at an earlier stage. Similarly, to make a decision based on chronological age, to start at a more advanced level could make the entire exercise meaningless. Whatever stage we consider appropriate to the abilities of the person involved it is best to begin with a limited number of objects which refer to real concrete events (e.g. meal times – a spoon, music – a tambourine) and which, in the case of real objects are a component part

of the activity (e.g. the spoon is used to eat the meal). The choice of objects with which to introduce this mode of communication should be clearly associated with preferred or, at least tolerated, activities in order to ensure optimum motivation for use.

Early stages:

the processes of teaching and assessment in this area of communication are inseparable. Each time an object is offered or indicated by the practitioner the action must be accompanied by a careful observation of the deafblind person. We should be constantly watchful for any sign of understanding or anticipation, e.g. a spoon being put into a hand may be accompanied by an opening of the lips, or the other hand seeking a plate which could indicate early awareness that the spoon is a signal for food. This anticipation, and the accompanying understanding, can then be developed by a slow and gradual distancing of the signifier from the event so that, for example, eventually a deafblind person on being presented with their spoon in one room may make their way (independently or with help) to the dining room in the confident knowledge that their meal is about to be served.

Later stages:

the concepts of significance and symbolisation will be acquired at different speeds and to different levels by different individuals but the rate and level of symbolisation (from real object the written/ brailled word) will be entirely based on the needs and strengths of the individual. Some individuals will require a growing repertoire of real objects, others to have objects replaced by parts of objects, miniaturised versions or two-dimensional drawings

or pictures. At this stage, objects or other signifiers may be used in conjunction with calendar boxes, timetables, communication files etc. and it is important to realise that, for those who are able to progress to more widely used modes of communication such as gesture, sign, speech, writing, reading etc. then the use of objects of reference is only a stage.

Moving on:

at each stage, between real object and miniature, between object and picture and beyond, the need for clear and coherent transition is clear. Eventually a need may arise for a growing abstraction in objects of reference (e.g. objects for yes/no). At this point, it is likely that an individual will be better served by progression to a communication mode, such as gesture, which is more widely understood in society and therefore more powerful in day-to-day life. Objects of reference are augmentative i.e. they support other modes of communication and, for many deafblind people will eventually be to a greater or lesser extent, overtaken by other methods.

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'Attachment' – theory into practice

In this case study of Jamie – an eight year old deafblind pupil, Ann Major, an Advisory Teacher in Gwent, South Wales discusses the vital role his family has played in his development.



Ann Major

I have been a 'student' of deafblind principles and methodologies since 1993, the date of my appointment to steer the newly established deafblind provision in South Wales. Children with multi-sensory impairment (MSI) were then and continue to be a source of fascination, partly because of the diversity of their sensory impairment aetiologies but also because of their unique abilities, aptitudes and personalities. These children are educated following a particular paradigm, founded on the practices and ideologies that have their foundation in Canada, with the work of McInnes and Treffry (1982) and van Dijk (1986) in the Netherlands.

After 7 years of study I recently experienced 'the penny dropping' phenomenon, (rather like the way in which I was taught maths at primary school; learning the rules first only to find that understanding the concepts developed many years later in some bizarre practical situation). Like many practitioners starting out in the field, I have had to first rely on the theory that has become the bedrock of MSI teaching practices. The importance of early bonding – as advocated by Bowlby (1979) and supported by van Dijk (1999) as the starting point for developing communication and interaction with MSI children.



The Importance of Attachment

In evaluating the successful transition of a young pupil with multi-sensory impairment from home to his local nursery class and then to a mainstream primary school, this principle has to be the overriding factor that has provided the security and confidence needed for him to 'successfully deal with the outside world'.

The following case study outlines Jamie's development and his mother Gaynor's attempts to engineer her son's early years.

Jamie's Progress

Jamie was born at thirty weeks gestation. He had been affected by the rubella virus which Gaynor had unknowingly contracted early in the pregnancy. She had been 'rubella immune' when her first child was born. Consequently Jamie was of low birth weight, he had a profound hearing loss, congenital cataracts, glaucoma, heart defects (due to a very narrow pulmonary artery) and a hernia. After the birth Jamie was 'taken away' and not seen by his mother until he was two days old. His entrance into the world had been met with very negative reactions. At four days old and fighting to survive, Gaynor was told to 'expect the worst'. However, Jamie's character, 'feisty and determined', (which was to be an important factor in his development), was already evident and at eight weeks he was allowed home.

The family were pleased to have Jamie and Gaynor home. However the stress of 8 weeks hospitalisation paled into insignificance when compared with the events which followed. Community professionals 'took over' Jamie's care. The scenario will be familiar to many parents. On the first day home, the Health Visitor called. On the second day the Social Worker visited

along with a worker from the local Association for the Blind. Within the next few weeks Jamie was visited by the Occupational Therapist, the Physiotherapist, the Community Paediatrician and eventually the Educational Services for Children with Hearing and Visually Impairment who very quickly set up weekly home intervention programmes.

The personnel listed became frequent visitors; so much so that Gaynor recalls that at one stage, she had only 'one day off a week'. Daily life fast became fragmented by callers and this was in addition to the fortnightly visit to Great Ormond Street Hospital and the monthly appointment at the audiology clinic.

Gaynor felt that she was in 'overdrive' with advice. However, whilst realising that she needed the help and guidance of professionals, her intuitive thoughts reminded her that she also needed to keep firm control of her key role – mother! No-one had written a book on her *particular* child. How then could professionals know so much about Jamie's needs? Gaynor would have been interested to read about Jan van Dijk's work (1999) which describes the importance of consistent caregiving in multi-

The personnel became frequent visitors; so much so that Gaynor recalls that at one stage, she had only 'one day off a week'.

sensory deprived children.

Gaynor believed her maternal instincts had proved to be very successful in raising Jamie's brother Paul, who was 18 at the time of Jamie's birth. It was strange therefore that she found herself 'listening' to the many experts who provided advice and guidance on aspects of Jamie's development. She now smiles when reflecting on how, once the door had closed, she was left alone to put into practice the innumerable strategies / activities that had been suggested 'to promote vision', 'increase tolerance to hearing aids', 'improve feeding / weight bearing' etc. until the professionals next visited when more advice would be at hand.

The question of school was first raised when Jamie was 18 months old (and weighed 14lbs!). It was

age and legally had to be educated! During this time she remained the key worker in Jamie's life, co-ordinating the input provided by the multi-disciplinary team involved with Jamie.

Gaynor decided that at 5 years of age, Jamie was ready for Nursery school. He was now walking with assistance. A special school was also out of the question. Jamie had to live in the real world – his experiences, just like those at home had to be real and parallel those of his brother and cousins. Jamie was bright, alert and able to learn, and in Gaynor's view, he was certain to succeed.

Jamie began attending the nursery class part time at the local Infant School in July 1997; one hour a day for two days a week, accompanied by his mother. In September 1997, two years behind his chronological age group, he joined the new nursery class cohort, again accompanied by mum and a qualified Nursery Nurse who was to become his key worker for the term.

The transition was carefully orchestrated by Gaynor, who worked alongside the key worker and gradually withdrew once she was satisfied that Jamie was happy with the routines of the morning. This was an enormous wrench for her; she admits to first sitting in the hall, then moving further away to the school car park to sit in her car, then parking the car in the street and finally returning home only to collect him at lunch time. This was the first time in 5 years that Gaynor had left Jamie in the hands of an 'outsider'. Gaynor's position as key worker had now transferred to another adult. Gaynor remained hesitant, particularly as the key worker

No one had written a book on her particular child. How then could professionals know so much about Jamie's needs?

proposed that Jamie should attend a special school when he was two years of age.

Jamie was the size of a 3 month baby and Gaynor's first thought was 'what would a three month old baby do at school?' Gaynor realized that Jamie would not be reaching his developmental milestones at the expected chronological age. It would take some time and she wanted desperately to be the person who witnessed these, just as she had done with her first son.

It was to be 3 years later that Gaynor conceded to pressure for Jamie to attend school and this was because he was of statutory school





Gaynor continued to face pressure from a few professionals who advocated a special school placement for Jamie.

changed, but the professional appointed was to become very committed to Jamie's needs and keen to further her knowledge of multi-sensory impairment. She attended the Sense Intervenor Course at Birmingham and has since gained her Stage 1 British Sign Language Certificate. She still works with Jamie.

Gaynor continued to face pressure from a few professionals who advocated a special school placement for Jamie. While the nursery setting met his needs developmentally, Jamie's communication needed a different thrust. Receptively, he was understanding a range of pictures and signs and was beginning to express himself using gestures and signals. It was clear that a signing environment would allow him to develop these skills. A primary school with a class for hearing impaired children was considered and Jamie subsequently transferred to the school with his intervenor in September 1999.

Jamie is taken to school by his mother who returns to the school at lunch time to assist in his feeding programme. However, in other areas of his development, he

continues to astound the professionals. Jamie has a signing vocabulary of approximately 20 words and uses 2 word 'utterances' to respond to questions. He attends a mainstream class with his intervenor for Science and P.E. and has developed friendship links with his peer group. The placement has been viewed as a success and Gaynor is grateful to the Local Education Authority for supporting her wishes and aspirations and for making available a range of resources to meet Jamie's needs.

And what about the future? Hospital visits will continue – ocular examinations to ensure the glaucoma remains in check, audiology visits, tooth extractions and the inevitable heart and hernia surgery. Jamie remains under weight and will need to be monitored by both the physiotherapist and the occupational therapist. Feeding and nutrition is a major concern and Gaynor continues to visit school to be involved in the lunchtime feeding programme. She therefore currently oversees the 'therapy' aspects of his development. As for academic progress, which

always depends on the willingness of the learner to be an active participant, the secure bonding that developed within the early years has provided Jamie with a platform on which to build future relationships. Meanwhile, Gaynor, for all her efforts, can now take a back seat – happy for the professionals to remain in control, steering Jamie towards increased autonomy.

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CHARGE NETWORK

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EUSN - EUROPEAN USHER SYNDROME NETWORK

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NETWORK NEWS

Charge Network

It's been a relatively quiet summer for the Network as the behind the scenes work gathers pace. Our first major activity will at the 5th Dbl European Conference in the Netherlands, July 2001 where we will be taking part in the Network morning.

The Network at present is trying to secure funding so that it can begin to function on a day to day basis rather than just hopping from one activity to another. There are many avenues to explore in this respect and we are confident that in time we will be successful.

We have a new addition to our Development Group – David Brown. This is tremendous news for us because David brings with him a vast amount of experience and knowledge, both on CHARGE and on multi-sensory impairment. Actually it could be said that David sowed the seeds for the establishment of the CHARGE Network. In Cordoba, Argentina in 1995 at the XIth Dbl World Conference David gave a talk on early intervention and he mentioned the condition known as CHARGE. After that David then became a focus for enquiries! Initially several countries in Europe and South America were involved and David was often e-mailing and faxing information and material to professionals and families hungry to know more.

David has recently joined California Deaf-Blind Services in the USA but prior to this he worked devotedly for 15 years at the Sense Family Centre where he specialised in early years children.



David Levey

David met many children with CHARGE whilst working for Sense and became an integral part of the CHARGE Family Support Group, both as a member of their management committee, and as host for their Family Days. David also attended several CHARGE conferences in Australasia and the USA.

David Brown was the driving force behind Sense's work with CHARGE and we look forward to the contribution he will make to our Network.

Contact Person

David Levey
CHARGE Development Officer
Sense

NETWORK

At the European Conference there will be a morning dedicated to the work of Dbl Networks.

This provides the opportunity for participants to catch up on activities and consider whether to join up themselves.

Network Coordinators should contact Anneke Balder at the Conference Office.



EUCO Unit/Staff Development Network

During the pre-conference activities of the 5th Dbl European Conference on Deafblindness the members of the EUCO Unit/Staff Development Network would like to present their work in Noordwijkerhout, the Netherlands, on 23 and 24 July 2001.

They would like to share:

- the principles that guide best practice training and development in the field of deafblindness
- suggestions of training components that address these principles
- the identification of available training materials/courses which meet these principles.

Speakers from deafblind services in Sint-Michielsgestel, Madrid and NUD will present their principles, recommendations and identifications relating to staff training and staff development. After the presentations there will be the opportunity to discuss the issues raised in small groups. During the plenary session groups

will give their reports and these will be followed by a panel discussion. We would like to conclude with a statement on how to move forward with staff training and staff development in a collaborative way at a European level.

Other Pre-Conference Activities

Title: Hands-on workshop on assessment and programming deafblind children

Date: 22, 23, 24 July 2001

Subject: Over the years Dr. Jan van Dijk has developed user friendly assessment procedures which relate to the basic educational questions of deafblind

children. These procedures will be demonstrated in co-operation with the deafblind experts Marleen Janssen and Bernadette van Tillaart during a hands-on workshop lasting two-and-a-half days.

For more information and an application form to attend please contact:

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Co-ordinator EUCO Unit,
Instituut voor Doven
Support International
Theerestraat 42
5271 GD Sint Michielsgestel
the Netherlands

Tel: +31 (0) 73 55 88 333 or
+31 (0) 73 55 88 310

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Email: ivd.international@ivd.nl



Leike de Leuw

EUSN – European Usher Syndrome Network

The European Usher Syndrome Network (EUSN) is a new group that has recently become eligible for recognition by Dbl as an emerging Network.

EUSN is for Usher people themselves, their families and friends, plus professionals who work directly with Usher people and their families, e.g. social services, teachers, employers etc.

There are currently 18 people in the group; Peter Palmer is the Chair and Carol Brill Doran is the Secretary. EUSN is a practical group and aims to share ideas, information and good practice

within its membership. The 6-strong Steering Group are currently planning their first conference, "Living with Usher Syndrome," that will be held in the Netherlands from 21-23 July 2001. This will be a practical conference led by people with Usher and their families.

The conference venue is: The Golden Tulip Conference Hotel, Leeuwenhorst, Langelaan 3,

2211 XT Noordwijkerhout,
the Netherlands
Phone: + 31 (0)252 37 88 88
Fax: + 31 (0)252 37 88 90



Marilyn Kilsby

All enquiries about the network or the conference should be faxed or emailed to Marilyn Kilsby on fax number:
+ 44 (0) 20 7272 3862 or email:
mkilsby@sense.org.uk

European Deafblind Network

Lex Grandia, Secretary of EdbN, introduces us to the structure and activities of EdbN and sounds a personal warning for the future...

In 1987 the ECDBS, European Community Deafblind Secretariat, was established by national representatives of deafblind organisations, family members organisations and professional organisations from the EU countries. In 1994 the Council meeting of ECDBS in Greece decided to change the name of the organisation to EdbN, (European Deafblind Network). The governing body of EdbN is the Council and the Management Committee.

The Council consists of three national representatives from each country: a deafblind representative, a family representative and a professional representative. Every four years the Council elects a Management Committee of three deafblind representatives, three family representatives and three professional representatives. The chairperson is elected by the Council on a rotational basis amongst the three groups.

The Council appoints a Treasurer and a Secretary. The Secretary carries out the day to day work of the organisation with the assistance of two part time employees, a development officer and an assistant secretary. The Secretariat is in Denmark, the Treasury in the UK and the Chairperson is Dutch at the moment!

Until 1999 EdbN had Council members from 14 EU countries (none from Luxembourg). A number of organisations from European countries outside EU have participated in EdbN activities and many have expressed a wish to become part of EdbN.

At the Council meeting in Poitiers, France in 1999, EdbN decided to welcome members from all European countries and in 2000 new Council members from Poland, Malta and Switzerland participated



Lex Grandia

in the Council.

The activities of EdbN are diverse and have developed over the years. EdbN has an annual Council Meeting and Seminar. EdbN has supported about 120 different multinational projects during the 12 years of its existence; conferences, seminars, study groups, cultural exchanges and meetings. Many of them were DbI network activities. Three very successful European Conferences for family members have also been organised.

EdbN circulates its own newsletter in print, disk and on the web (www.edbn.org) and has an email bulletin called the EdbN clipboard. For the past three years EdbN has received co-ordination grants from the European Commission. Although the organisation is based on voluntary work, it has become increasingly professional, improving the communication and information exchange between members and acting as an information and communication centre. As Secretary of EdbN and being deafblind myself, I represent the organisation on different European and International bodies. The

membership of the board of the European Disability Forum, EDF, and some of its commissions is very important. This allows us to co-operate with other European disability organisations in a way that is increasingly necessary considering that the climate of political will to support European disability organisations is decreasing.

The challenges for deafblind people in Europe – a personal view

A lot of barriers need to be removed before Europe will be accessible to deafblind people. The level of services for deafblind people are very diverse in Europe, ranging from paid guide and interpreter services, publicly funded communication equipment and leisure activities, to absolutely no services.

In many countries deafblind people are dependent on the assistance of volunteers, who often have had no basic training. There are countries in Europe who do not recognise deafblindness as a unique disability, where deafblind people have not been identified and no services exist for deafblind people.

Lack of services in many countries mean lack of education and job opportunities for deafblind people. Deafblind people have to devote most of their time to getting an education and later a job, and for many there is no spare time for organisational/voluntary activities. In many European countries there is no independent deafblind organisation.

Deafblind people are often part of an umbrella organisation with

family members and professionals or members of Blind or Deaf organisations. Because deafblindness is a low incidence disability it may be difficult in some countries to find deafblind people who are able and willing to do organisational work on a national and international level and others who can provide the necessary support for deafblind people to do this work. National organisations of deafblind people have expressed the strain it puts on their organisation to participate in international activities and some have actually withdrawn from international work. Many deafblind people need 2-3 interpreters and/or

assistants to travel to meetings, and translation of documents into their national language puts an additional strain on the poorer organisations. For many organisations it is a question of priority to participate in European and/or International work, and to decide which organisation to be involved in. Not many will be able to find the resources to participate in all the different bodies: the EBU Deafblind Commission, EDbN, EDBU and the new World Federation of Deafblind People (who are having their founding general assembly in October 2001 in New Zealand). These are some of the challenges we face in the

deafblind world. However, it is necessary for a small group like ours to work on an international level. It is only by exchanging information, experiences and ideas between countries and campaigning together, that we can strengthen and improve the situation of deafblind individuals and their families.

Acquired Deafblindness Network

In October the Co-ordinating group of the Acquired Deafblind Network met in Zurich, Switzerland. The venue was chosen to enable a meeting to take place with representatives of the Swiss National Association for the Blind.

SNAB have been working with acquired deafblind people for many years but have not become involved with DBI before now because they were unaware of emerging interest and work with acquired deafblind people. The meeting revealed a wealth of experience in Switzerland and Norma Bargetzi of SNAB has now joined the Co-ordinating group of the Acquired Deafblind Network.

It was agreed at the October meeting that SNAB will host a European seminar for practitioners in the field of acquired deafblindness in Switzerland in 2002. The dates and venue are yet to be arranged but will hopefully be ready for the next issue of *DBI* review.

A questionnaire intended to create a directory of all practitioners



Ges Roulstone

in the field of acquired deafblindness has now been issued. We hope to create a "knowledge map" of the skills and experience of existing practitioners. This will be vital for new practitioners in this growing area of work with deafblind people to use.

Sense East in the UK is co-ordinating this process. For more information on the questionnaire please contact:

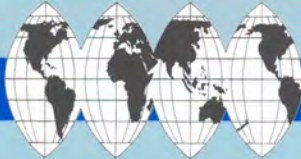
email: enquiries@senseeast.org.uk
Tel: +44 1778 344921
Fax: +44 1778 380078

Members of Acquired Deafblind Network came together in Brussels

in September to discuss the outcomes of work to bring together training materials for people working with elderly acquired deafblindness. Lega Del Filo D'Oro of Italy, Dienstverleners Gehandicapten in the Netherlands and Sense in the UK were principle partners in a project part funded by ESF. A CD-Rom containing useful information is now available from:

Sarah Greaves
Sense West
Tel: 0777 915 1491 (mobile)
4 Church Road
Edgbaston
Birmingham
B15 3TD

One principle outcome of the weekend meeting in Brussels was agreement on the need for better research on the numbers of elderly acquired deafblind people in Europe. Research from Norway, Finland and the UK has produced different results and trends. The Euro Acquired Deafblind Network has agreed to carry this important work forward via the European Conference in 2001.



Latin America

Ximena Serpa, Poscal co-ordinator, reports on a Training course for non-professional interpreters ...

The Poscal project (Program to create an Association of deafblind people in Latin-America) started in 1995 with the five Andean countries: Venezuela, Colombia, Ecuador, Peru and Bolivia. In 1997 there were 10 more regional countries that joined it: Argentina, Brazil, Chile, Uruguay, Cuba, Dominican Republic, Mexico, Nicaragua, Guatemala and Honduras.

Actually, in Poscal twelve associations of deafblind people have developed and more than 300 further people have been found since our last report – making a total of more than 1600 deafblind adults.

In these regions the government does not pay for the interpreter service for deafblind people, as in some developed countries. For that reason the deafblind person in our countries has to “use” friends and family members to act as interpreters for all their activities and needs.

It is only in Colombia that we have “professional interpreters for deaf and

deafblind people”, trained with the support of the Swedish Deafblind Association (FSDB) and the Swedish Handicapped Aid Agency (SHIA) through the Poscal project.

Bearing in mind these two points, the Poscal administration decided to offer training courses for friends and family members of the deafblind people.

They could then learn more about deafblindness: communication systems, aids, community organisations, interpretation, guide-interpreter's role, ethical aspects, orientation and mobility and visual description techniques.

The course took 48 hours and was offered to people who had been selected by the association members in each country. The “students” agreed with the organisations to continue working as guide-interpreters for the deafblind members.

Up until August 2000, the training courses had been



Ximena Serpa

offered in nine countries!

One of the Poscal goals is to identify more deafblind people in each country who can benefit from it's Association's programs. In any case, we think that these training courses will have to be repeated periodically to cover new families and friends of members.

In considering further developments we put together what we called a “multipliers course”. It was taken by selected participants of the first course and disseminated to six countries.

This Autumn we have been considering ways to keep this exciting programme moving forward, and we will keep you posted.

Lithuania

The seminar in Vilnius, in May was organised by CNEFEI and DBI Communication network with the support of Hilton Perkins, the EU Socrates Comenius programme and Sense International

Dalia Tauriene, Special teacher for deafblind children, Lithuanian Training Centre for the Blind writes...

Eleven countries were represented at this important event:

Czech Republic
Slovakia
Romania
Hungary
Russia
Poland
Estonia
Lithuania
Norway
Denmark
France

During this seminar video clips of interactions between congenitally deafblind people and partners were studied and analysed in order to identify the relevant principles to support the inclusion of congenitally deafblind people in communicative relationships as equal and active partners.

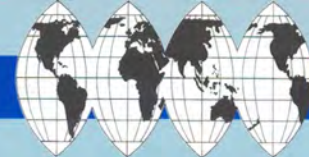
A video cassette will be one of the results of this seminar. Three sequences from Lithuania, Romania and Poland were chosen to illustrate the major aspects that were identified as most important during this seminar.

■ The first one shows how to sustain the interaction with the congenital deafblind person.



Dalia Tauriene

- The second sequence shows how the child creates gestures when shared interaction with an object is sustained and ritualised.
- The third one shows a child joining the adult in a new activity during which we see how negotiations emerged out of the relationship.



Argentina

Graciela Ferioli
writes...

It is in a busy metropolis, Buenos Aires, capital of Argentina that you will find the Rehabilitation Hospital named after "Manuel A. Rocca". It houses the specialist department of visual impairment and additional disabilities. Since its reorganization in the 90's this department for the deafblind and multi-handicapped has grown day by day, both in numbers and in quality. This has been possible through the provision of on-going training with a transdisciplinary focus using a team to cover the diverse issues of how to work with children and their families. Also, it is probably due to the materials provided about the different departments that facilitate better educational and therapeutic procedures for newborn babies and children in their early years – up to six years of age.

The complexity of the children's difficulties and concern for the families made the members of the team (social worker, educational psychologist and occupational therapist), go out of the hospital to evaluate each child in a real life setting. They began to visit families, gathering data that allowed for more effective



Families in the Rocca Hospital program

plans to be made, which fitted into family culture and their own environments. Recently, the team has needed to offer assistance to other professionals in areas where children live because sometimes they cannot attend the hospital regularly.

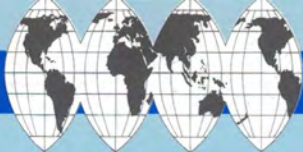
This demand encouraged the team to organize Extension Services that avoid drawing children out of their own settings, so the department has got better results. Families who ask for our services come from communities a long way away, so transportation, from

time to time, complicates the work. Moreover, we find homes that do not have the suitable functional stimuli for children. Likewise, the inclusion of children in institutions needs team working among professionals to reach the objectives to be achieved.

Undoubtedly, the development of the Extension Services demands changes in the attitudes of team members to allow thinking and acting *beyond the hospital boundaries* to improve the resources in the community.

Now this challenge has been accepted, the service has to examine which children's needs are more satisfactorily met in their own home settings. Finally, Rocca Hospital is the first service in Buenos Aires that offers home-center educational programs. Hilton-Perkins Program of the Perkins School for the Blind and Conrad N. Hilton Foundation make this possible with a grant to the department for visual impairment and additional disabilities.





Romania

New Developments

Cristiana
Salomie

The first services for deafblind people in Romania were established in 1999 but since 1997 Sense International has been actively supporting the development of services for this largely neglected group – with fantastic results.

The most exciting projects to date are the establishment of two educational programmes for deafblind children, one at the Eminescu Kindergarten in Bucharest and one in the School for Visually Impaired Children in Cluj.

It is anticipated that the kindergarten in Bucharest will grow and develop into a centre of excellence in the coming years. In March this year the Ministry of Education issued an official order concerning the education and the rehabilitation of disabled children in Romania and the Chief Inspector for Special Education is committed to starting more deafblind programmes after the evaluation of the current projects.

On the 12th October it was a great honour to receive a visit from HRH The Princess Royal at the Eminescu unit. The visit was a great



Cristiana Salomie introduces The Princess Royal to Romanian colleagues

opportunity for us to raise awareness of deafblindness amongst the general public and the Government, thereby increasing opportunities to gain support for the great number of deafblind people in Romania. HRH The Princess Royal was very pleased with the children's achievements and spent a long time with teachers and parents, sharing with them hopes and ideas and greatly encouraging them. On the same day HRH The Princess Royal unveiled the plaque

inaugurating the new office of the first ever Association of Parents of Deafblind Children. This was formed as a result of the initiatives of parents from the Eminescu Kindergarten and is now a National Association.

Other future projects in Romania include plans for a joint conference with UNICEF on multiple disability, a project on interpreter services and communicator guides with the National Deaf Association and a project for deafblind adults in Timisoara.

Russia

Galina Epifanova, Chief Executive of the Children's House for the Deafblind in Sergiev Posad, Russia writes;

A delegation of teachers from the Children's House for the Deafblind in Sergiev Posad, Russia, recently travelled to Vilnius, Lithuania, to take part in the seminar on the Development of Communication for Congenitally Deafblind People. Our attendance was made possible due to support

from the Hilton Perkins Foundation. Listening to lectures about Communication, discussing and analysing video materials and getting a practical evaluation of our own video footage from other specialists in the field was an excellent opportunity for us. The information we received at the seminar will help us to find new methods to use in our work and will greatly benefit us in the future.





Russia

Spreading the Word

Irene Salomatina from the influential Usher Forum reports ...

It has become a tradition in recent times that the Moscow Deaf Association celebrates the International Day of the Deaf by organizing a week of special events. In 2000 it was the third time this has happened. The programme included a symposium on the Social Rehabilitation of Deaf People. As the Usher Forum has already created good relationships with Moscow Deaf Association we were invited to present two talks on the aspects of social rehabilitation of deafblind people, giving advice on the way to support deafblind people within a Deaf

Association. We were pleased that participants from other states, such as Azerbaijan and Germany, could listen to the reports on the experiences of the Usher Forum in raising awareness on deafblind issues in the deaf community in Moscow.

The other step to broaden awareness – this time in the blind community – was made at an All-Russian conference for State Libraries for Blind People. Representatives from 72 regional libraries for the blind gathered in Moscow to discuss the present state of specialised libraries throughout the country. Once

again, the administration of Moscow State Library for Blind people invited the Usher Forum to advise the staff of these libraries on how they could meet the needs of deafblind users more effectively. Everybody agreed that consultation and co-operation in the exchange of information are the best ways to begin. A leaflet "If a deafblind person comes to your library" was given to each participant of the conference.

irv@child.ru
ivsai@mail.ru

UK

Sense International wins major award

Sense International has been voted the official British International Charity of the Year as a result of the impact it has been making for deafblind people.

At the first ever UK charity awards held in June 2000, Sense International triumphed over more than 150 nominations to win the International Development Charity of the Year Award. These national awards, specifically recognised

quality of management and excellence in the voluntary sector.

Sense International was selected by ten expert judges on the grounds of "the unique development approach adopted to increase the services offered to deafblind people in India". Three years ago there was only one school in the entire country providing a specialist service for deafblind children. Since then the number of deafblind services has risen to 15. The Charity Awards noted that this has been achieved in an inclusive and cost effective way.

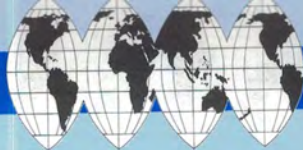
Many of the best known figures from the UK voluntary sector attended a gala dinner to present these Charity Awards at the Savoy Hotel in London. Sense International's award was presented to Richard Hawkes by Andrew Hind, BBC World Service, who said "Sense International had the edge in the way that it tackled the enormity of the challenge to develop

services in India from virtually nothing".

It is a tremendous honour for Sense International to win this award and fantastic recognition for deafblindness as a disability. The standard of voluntary sector management has become an increasingly important issue for all organisations and receiving official recognition such as this enhances Sense International's ability to attract supporters and partners. It is also reassuring that the unique approach adopted by Sense International to supporting sustainable developments for deafblind people has been acknowledged by colleagues within the sector. The award is a credit to all Sense International staff around the world, but especially to Akhil Paul, his team in India and all of the partner organisations who have worked so successfully with Sense International in recent years.



Sense International India team



France

A major development in support for deafblind people – CRESAM is now open!



Jacques Souriau

Services for deafblind people will be improved in France thanks to the opening of a National Resource Centre called CRESAM (Centre de Ressources Expérimental pour enfants et adultes Sourds-Aveugles et sourds Malvoyants, which means Experimental Resource Centre for deafblind and deaf children and adults with residual vision). 10 staff members are in charge of implementing 9 missions defined by the Ministry of Social Affairs:

- To develop a data bank relative to the characteristics of the handicap and to the methods of dealing with it.
- To circulate adapted information to the technical and professional teams.
- To evaluate the relevance of new prophylaxis, detection or treatment methods.
- To make or improve the diagnoses
- To help and train the teams in the institutions to develop an institutional plan and individualised plans.
- To study the required technical conditions to favour maintenance at home if it responds to the family's desire.
- To inform and advise



isolated families and to put them in touch with the aforesaid institutions.

- To inform and advise adults living at home and the professionals who work in contact with them.
- To establish the protocols necessary to prevent regression in children as they become adults.

Most of staff members are also working part time in other services for deafblind people.

During the negotiations, two different Resource Centres were designed: one for the deafblind children, the other one for the adults. In the end, it was decided that both parts should be united under the same administration. The Resource Centre has to deal with categories that usually are addressed separately: children and adults with congenital and acquired deafblindness. This situation makes it necessary to divide the tasks among staff members so we identified the following categories:

- congenitally deafblind children
- children with Usher

Syndrome in a normal school setting or in schools for the deaf

- adults with congenital deafblindness
- adults with acquired deafblindness
- old age

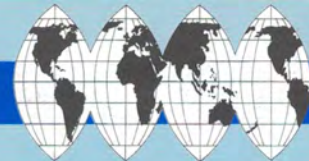
The work in CRESAM has two aspects:

- Direct interventions for deafblind people through collaboration with local services. This action requires an assessment of individuals and their setting, staff training and staff follow-up. In the long run, further de-centralisation will be required.
- Actions on specific topics.

In order to improve the quality of services to deafblind people and families, CRESAM developed actions focused on groups of people on specific domains. Among them, we can mention:

- supporting staff developments in the field of elderly people
- training of interpreters for deafblind people
- research into sleeping





difficulties in deafblind people

- studies on the development of children with CHARGE Syndrome with the collaboration of the family Association

- information on Usher Syndrome

- a documentation service is being organised.

Information on deafblindness can be found on our web site

(www.cresam.org) and people interested in the French version of *DbI Review* can read it on the web site (centre.res@cresam.org) or it can be ordered on paper using the following address:

Jacques Souriau
Director
Centre de Ressources
Expérimental pour enfants et adultes Sourds-Aveugles et sourds Malvoyants
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Email :

centre.res@cresam.org

Web site : www.cresam.org

Parlez-vous Français?

If you prefer your information in French why not visit the CRESAM website at www.cresam.org

Argentina

Yvonne Ramos

ASAERCA, The Association in Argentina which was founded to promote the study and rehabilitation of the blind met together between the 19th and 22nd of October, this year for their 15th "Jornada".

This time it was Buenos Aires, the capital of the Republic, that hosted the professionals, parents, companies and people with, and without, visual impairments to get together to discuss the idea "Technologies to deliver a More Accessible World".

This was a great opportunity to explore the theme in relation to the problems that face people with challenging complex disabilities – including those who are deafblind and with multiple disabilities.

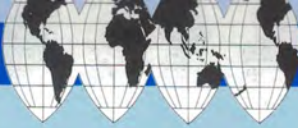
Professor Graciela Ferioli was Chair of the Scientific Committee and this special group of multi-disabled people, and their needs, had been central to many discussions previously.

There were frequent opportunities for exchanging ideas and views and with such a dedicated group of people, from such a range of backgrounds (which included the Rocca Hospital staff) the conference was lively and full of possibilities for the future.

Jarmila Havlik and Osvaldo Bertone joined Graciela on a panel discussion about the technologies available for people with multiple difficulties. In a complementary workshop, specialist resources for

people with visual impairment and additional disabilities were discussed.

Without doubt, the contributions that poured out contributed to the enrichment of all those who participated and as a consequence the knowledge and understanding that was shared will have a positive impact on the lives of people challenged by multiple disabilities and their families.



India

The First Teacher Training Course in Deafblindness begins...

The first ever Teacher Training Course preparing teachers of deafblind people in India was inaugurated in Mumbai on 11th of July 2000. The course is run by the Helen Keller Institute for the Deaf and Deafblind, Mumbai and is sponsored by Sense International (India).

With only a few services available for India's 300,000 deafblind population it was important that if there are going to be a large number of services for deafblind people, there must be qualified staff and teachers working in these programmes. There is an urgent need to develop human resources through the professional training of teachers in this field.

The Helen Keller Institute for the Deaf and Deafblind, Mumbai has pioneered deafblind education in India and Asia for over 20 years and furthermore has newly acquired premises with all the necessary infrastructure for training, library and lecturing facilities. Consequently, the development and delivery of a National Teacher Training



Biju Mathew

Programme presented an ideal opportunity for the Institute to collaborate with Sense International and other national and international colleagues. The ultimate aim of this course is to create and expand the pool of professionally trained teachers in the field of deafblindness throughout India, in order to provide greater support and opportunities for deafblind children.

The background

In 1998 a Working Group

was formed which comprised professionals from The Clarke School for the Deaf, Chennai, The Helen Keller Institute for the Deaf and Deafblind Mumbai, The National Association for the Blind, Mumbai, SNDT University, Mumbai and The Blind People's Association Ahmedabad and coordinated by the Director of Sense International (India). The curriculum has the official recognition of the Rehabilitation Council of India (RCI) which is the statutory authority under the Ministry of Social Justice and Empowerment, Government of India for approving training courses in the disability sector.

The course will train 10 teachers every year who will subsequently either establish new deafblind units within their respective organisations or deliver professional deafblind education to deafblind students in existing centres. The course has inputs from international teachers and experts. Sense International will play a major role in coordinating these visits and consultations and in the monitoring and evaluation process. Experts within India will be used increasingly in the later part of the course as a core group of trained professionals to emerge in-country.

The course has already started and the first cohort of trainees has joined the Helen Keller Institute for the Deaf and Deafblind in Mumbai.



Teacher trainees with faculty of the programme



Canada

Rotary
Cheshire
Homes inc.

June is Deafblind Awareness Month!

Joyce Thompson, Executive Director of Rotary Cheshire writes:

"Earlier this year a delegation from Rotary Cheshire Apartments was in the Members' Gallery of the Provincial Legislature (Ontario) to witness the 2nd reading of Bill 125.

We were pleased to be able to watch the debate. Mr. Young's legislation recognising June as Deaf-Blind Awareness Month! It is greatly welcomed and

will assist in our efforts to expand the range of services available to people with Deaf-Blindness."

Deaf-Blindness is a disability that affects between 3000 and 7000 Canadians. While some individuals are born with deafblindness, most people acquire one or both of the disabilities later in life through trauma caused by an accident, or simply by ageing.

E-mail:
rcheshire@onramp.ca

A new website!

Announcing:
www.chkc.org

Lorne Marin has designed the new web site for the Canadian Helen Keller Centre, a division of Rotary Cheshire Homes Inc.

Comments and feedback would be appreciated. There will be new information added frequently. Keep in touch.

Australia

The "Keeping in Touch Beyond 2000 Conference" has been hailed as the best ever in Oz! It was held in Freemantle and covered a very wide range of interesting topics with excellent presenters. A major feature of the conference was the outstanding support that was available for all the sensory-impaired delegates – at any one time up to 24 interpreters



WEST AUSTRALIAN DEAFBLIND ASSOCIATION (INC)

were working simultaneously!

A new concept, the Voluntary Support Provider (VSP) was available to guide and facilitate before and after the formal parts of the day and dressed in red they were

easily identified.

The social activities included a fabulous cruise or a trip on a Paddle Steamer! The weather was brilliant as well – so congratulations WADBA!

West Australian Deafblind Association has released its second training video, "Where do I begin?" Developing communication with children who are born deafblind.

Our first deafblind awareness video, "Assume nothing", has had such positive feedback that we have been encouraged to produce another, this time focusing on some key strategies for developing communication with congenitally deafblind individuals. The three delightful children highlighted in this video were introduced in "Assume nothing". All are functionally deafblind, with varying degrees of hearing and vision loss, and ages range from 18 months to 12 years. Strategies are

demonstrated across various settings – home, school and therapy. Emphasis is placed on the importance of acknowledging the child's communication efforts.

Key strategies presented are primarily child-directed rather than adult-directed and include the following:

Making contact – 'Approach'
Building rapport
Using tactile cues and symbols
Tactile signing
Establishing routine
Choices
Interrupted routine
Acknowledging communication efforts

This 23 minute video is open-captioned and available in both

PAL (eg. Oz format) and NTSC (eg. USA format). It will also be available in DVD format shortly. PAL format is A\$27.50 plus A\$5.00 postage within Australia or A\$10.00 A postage outside Australia (including GST).

NTSC format is A\$35.00 plus A\$10.00 postage outside Australia (including GST).

Checks or money orders in Australian currency only can be accepted. Bankcard facilities are available. Ordering information from the WA Deafblind Association at <wadba@nw.com.au> or WA Deafblind Association 6th Avenue and Whatley Crescent (PO Box 14) MAYLANDS Western Australia 6051 Australia Voice phone: (08) 9 272 1122 TTY: (08) 9 370 3524 FAX: +61 8 271 3129

Reflections on 25 years of the Canadian Deafblind and Rubella Association



Stan Munroe

The idea of being an activist or an advocate in a disability organization was furthest from my mind

I can still remember that first meeting of parents, over twenty five years ago, at the W Ross Macdonald School in Brantford, Ontario, Canada. My son had been attending school in the Deafblind Unit for almost two years. I was comfortable with his disability and his place in our family, but I was not interested in being anything more than a regular parent. The idea of being an activist or an advocate in a disability organization was furthest from my mind.

That passivity would all change as a result of that meeting in early spring 1975. All families of children attending the deafblind program received an invitation to attend a meeting scheduled for just after the end of the spring school break. During this meeting I met other parents from the provinces of British Columbia, Saskatchewan, Manitoba and throughout Ontario who had travelled with their children to Brantford following the spring break. I soon came to the conclusion that associating with other parents was probably safe to do. It was also a revelation to learn that I was not alone and that there were other like minded people in the same family predicament.

What was so special that I observed about this group of mothers and fathers during that first meeting was that we all shared a common issue, that our child was disabled by deafblindness, primarily the result of congenital rubella. Everyone's personal story

had similar elements, including lack of understanding and compassion from the medical community, the numerous medical procedures and hospital visits, family pressures, despair about the future for their child, etc. What was also remarkable was that each parent shared a common vision or dream for their child, and we were all looking for mutual support and guidance to help each other achieve our vision and dreams.

So as we talked during these brief hours in Brantford, the thought began among all of us that a parent support organization could perhaps mean a better future for our children. The room was full of like-minded individuals that day, each who had experienced the same personal issues and shared the same visions. Prior to this gathering, each of us was alone, struggling to find the right connections and direction. Perhaps now, together we had found the right combination, and could successfully open the door to a better future for our child.

Putting the essentials of an organization together on that day in early spring appeared rather daunting, at least at the beginning. Iris Gilchrist, the more experienced parent (who was also a nurse), quickly took on the role as leader, and would become our first President. Mike Caruso, the lawyer, agreed to put together a Charter and apply for a Charitable number. Gerry Brogan, the business man, indicated he

could be counted on for strong administrative support. Myself, the civil servant, volunteered to take on the job of correspondence and bookkeeping.

Little did we realize that the organizers of this fledgling association would eventually assume the leadership of the organization throughout its first twenty years. After Iris Gilchrist served out her term as President, Mike Caruso, Gerry Brogan and myself (in that order) served as President of the CDBRA. Most of the original organizers have continued to be involved in deafblindness issues at various capacities, some at the Regional Chapter level, others on the Boards of Independent Living Residences and myself continuing with the national organization. For all of us, serving on organizations related to deafblindness has been a lifetime commitment; and a labour of love and necessity.

I must first acknowledge the early influence of Peggy Freeman and other pioneers from the UK Deafblind Association (Sense) in the early development of our organization. Peggy's ground breaking publication and her correspondence with our first President Iris were indeed important early influences.

Also, the participation of John McInnes and Jacquie (Treffry) McInnes were highly significant contributions to our organization. These two individuals, in my opinion, helped shape the vision and direction of the CDBRA. John

was the Assistant Superintendent of the W Ross Macdonald School and Jacquie was the Supervisor of the Deafblind Unit. They recognized early on the importance and significance that parent power would have in developing future services for children and adults with congenital deafblindness. There was no dispute that professionals had the knowledge and dedication and parents had the commitment and vision. It would become clear that the power of these two forces (parent and professional) operating together would be most significant.

In my opinion, the development and implementation of services for individuals with congenital deafblindness in Canada was the direct result of parent and professional forces operating together. This synergism truly has characterized the success of Canadian programs for individuals with congenital deafblindness.

Over the past twenty-five years CDBRA has shown significant progress as an advocacy, service delivery and service facilitating organization. We are not a large organization but are influential. The following outlines some of our achievements:

- The CDBRA has supported and promoted the Canadian concept of Intervention throughout the country, although we cannot take complete credit for its development. Currently the organization administers a host of Intervention services programs across the country.
- It has been instrumental in establishing a network of independent living

residences in the provinces of Ontario, Manitoba, Saskatchewan and British Columbia.

- There is a program in the province of New Brunswick providing varying amounts of Intervention services to individuals with congenital and acquired deafblindness. This program is administered by a parent who was one of those original organizers of CDBRA over twenty five years ago.
- In the province of Manitoba, the CDBRA has been successful in providing Intervention services to a number of persons living in an institution who were previously not identified with deafblindness.
- The CDBRA produces four editions of the news magazines 'INTERVENTION' devoted to Canadian deafblindness and parent issues. It has been producing this magazine for over 20 years.

Even after twenty-five years there is still so much more to do here in Canada with respect to deafblindness. The CDBRA, and cooperating professionals and volunteers, have indeed had an impact on the lives of those born since the mid-1960's with congenital deafblindness. Many of these individuals have been educated in special facilities for deafblindness or in regular school programs in the individual's own community. Many young adults have also been provided with supported adult living arrangements, either in group facilities or in independent situations.

But so many others with deafblindness need support and services to improve their quality of life. Many individuals with acquired deafblindness

(and they represent the vast majority of individuals with deafblindness) deserve a much better quality of life. This could be ensured through better services, including access to Intervention, special housing, technology training programs etc. There are also numerous visually and hearing impaired individuals born before the early 1960's and living in Provincial Developmental Centres (formerly called Psychiatric Institutions, among other names) and Community Living Homes who are not identified as deafblind and could benefit immensely from Intervenor services.

The challenge in the future for people in Canada with deafblindness is multi-fold. We must first ensure that the current service provisions for those with congenital deafblindness continues and is not diluted. The services which are so successful in some parts of the country must be available in all regions in Canada and be consistent. Furthermore, the opportunities for Intervenor services and quality housing must be available to everyone with the deafblindness disability to ensure their quality of life. In my opinion, the key to ensuring that all deafblind persons have the appropriate services and achieve a better quality of life is to bring these individuals directly into the process. We are well aware in Canada of the power of synergy of parent and professional connections working for the congenital deafblind. Just imagine the power of synergism by adding the deafblind person to this equation! This could mark Canada's success for the next 25 years to add to its accomplishments in the last quarter of the 20th Century.

The challenge in the future for persons in Canada with deaf-blindness is multi-fold.

Kim Wrigley-Archer



Kim Wrigley-Archer

Kim Wrigley-Archer distinguishes herself as being a working parent, a wife, and an advocate for persons with deafblindness. Despite having a profound hearing loss diagnosed as an infant, Kim did not learn that she had Usher syndrome until she was 20 years old when an eye examination revealed the condition Retinitis Pigmentosa or RP. A year later, Kim decided she should go to university and prepare herself for the future. While at Brock University in St. Catharines, Ontario, Kim met Bruce Archer, who, whenever she was discouraged, motivated her to 'hang in there' and finish her education.

Kim earned her Bachelor of Arts degree in 1979 and is currently employed as a systems developer with a major Canadian bank. She and Bruce have a seven year old daughter, Jaimie. Since Usher Syndrome is transmitted through recessive genes, Jaimie is a carrier, but will not develop the condition herself.

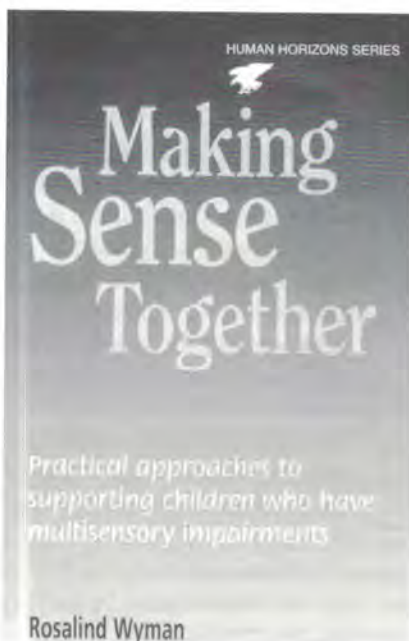
Kim was involved for many years with the RP Research Foundation, an organization supporting retinal eye research. She has participated in numerous Rides for Sight and facilitated a successful hearing/vision loss workshop at one of the RP Vision Quest conferences. Kim

believes that, through research, effective treatment for RP will eventually be found.

According to Kim, "many deafblind adults living independently in the community are desperately isolated and tend to 'fall through the cracks' in terms of receiving appropriate services. Being unable to access basic communication and information has profound impact on the quality of daily life for these adults". She indicated that she is currently working with a group of dedicated people who want to establish an Outreach Centre that will offer services to help bridge these gaps.

Making Sense Together

by **Rosalind Wyman**



This is the book we wrote briefly about in the last edition of Dbl review when we celebrated Lindy's retirement from Sense. It draws on her life's experience in supporting

families, particularly in the early years.

This is a revised edition of the book she first published in 1986 (Multiply Handicapped Children) and it has been substantially rewritten to take account of changing approaches and educational practices. Its scope has broadened to cater for many children with multi-sensory-impairments who attend mainstream schools, and with its advice on materials and books it offers all those working with parents and children who have multi-sensory impairments a uniquely valuable guide to practical approaches that reflect the needs of present-day young people.

ISBN 0 285 63510 7

Published by Souvenir Press in the Human Horizons Series

Price £9.99

Free Computer Manuals for Blind & Visually Impaired People

Michael Maardt, from KnowWare Publishing in Denmark, is publishing free computer manuals for blind and visually impaired people. These come in 3 different formats: HTML, Ms-dos text with line breaks and Word. Titles include 'Escape from the Mousetrap' – 30 pages on shortcuts for Windows and how to use them. Other subject areas are to include Word, Excel, the Internet, and Homepages. For more information please visit: <http://www.KnowWareGlobal.com/blind/>

This address is not shown on Michael's website in order to prevent people with vision from accessing the files that normally cost money!

The girl who used touch to “See” and “Heard” through her heart

by **Maria Podhajecka and Janka Sarisska**



**Maria and
Janka (seated)**

This book has just been published in Slovakia and describes how the deafblind girl, Laura Bridgeman was the first to be educated at the Perkins School, Boston USA in the last century.

The book records Laura's life before she started at school: the influence of her mother and her uncle on her development and the approach they used to help her learn. It relates the importance of her teacher S.G. Howe and his interest and skill as a teacher. His ground breaking work with Laura was to ensure that other deafblind children were able to become students at Perkins.

The book contains Laura's correspondence as well as an

analysis of the ways of working which helped Laura to learn: in particular those approaches that are still useful today in the author's school in Slovakia.

About the Authors:

Dr Maria Podhajecka is in the Department of Pedagogy and Psychology at Presov University.

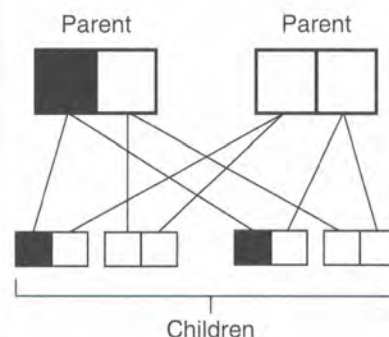
Janka Sarisska is Director of the Deafblind School in Slovakia.

Maria and Janka have worked together in the field of deafblindness since 1992 and Janka is a member of the Scientific Committee for the Dbl European Conference to be held in the Netherlands next summer.

Correction and Apology

In our last issue in the series, “Conditions and syndromes that can result in deafblindness” we inadvertently printed incorrect data on the inheritance pattern in **Stickler syndrome**. We consider this to be a serious error and enclose a correction “patch” for page 39 in Dbl Review Number 25.

Pattern of inheritance for Stickler syndrome



Key

-  Affected parent with Stickler syndrome
-  Unaffected parent
-  Affected child with Stickler syndrome
-  Unaffected child

We apologise to the author Fiona Hall-Jones.

Self Determination a life long process

Fifth Dbl European Conference on Deafblindness, 24 – 29 July 2001 the Netherlands

An update from the organising committee on the progress of the preparations:

Programme

Participants

Professional Organisation

Poen (Dutch slang for money)

Programme

The theme of the conference is 'Self Determination a life long process'. Nearly 100 abstracts for workshops and poster sessions have been sent in. Most of these are in line with the theme. The Scientific Committee is very happy that many of the papers are research based and about 150 authors are involved. When you read this, the Scientific Committee will have met. Authors will hear very soon if their abstract is accepted. The draft of the program will be published on the Dbl website in Spring 2001

Participants

At this moment we have some participants and a lot of interested people from all over the world registered. We hope we can finance the participation of colleagues from Eastern and Middle European countries. Unfortunately, the organisation of the conference cannot sponsor places for people from outside Europe. The conference centre can welcome more than 400 people in comfort.

Professional Organisation

Eurocongres is the name of the Professional Congress Organiser (PCO) that will guarantee that the logistical part of the conference will work well. The local organisation committee will guarantee a more personal touch in the whole of the organisation of this conference.

Poen

Getting enough (and a little more) Poen for this conference is one of the main concerns at the moment.

For more information:

Stichting Fifth Dbl European Conference on Deafblindness
Att. Anneke Balder
P.O. Box 222
3500 AE UTRECHT

Final Call for Registration for



'What it Means to be Deafblind: Identity, Rights, Unity'

The Seventh Helen Keller World Conference

&

World Federation of the Deafblind

First General Assembly

7-12th October 2001

Waipuna Hotel and Conference Centre, Auckland, New Zealand

The programme committee is currently finalising the details of this event that will incorporate both the Helen Keller Conference and the General Assembly of the World Federation of the Deafblind. The workshops and speeches will be presented over 5 days and will include a conference dinner and time for social activities. The committee hopes that this conference will lead to the development of better services and greater opportunities for deafblind people internationally – both educationally and economically. It is particularly hoped that it will increase Government awareness in New Zealand of the need for more services for deafblind people.

Papers to be submitted by 28 February 2001

For more information and a registration form please contact;
DBNZ International Conference
PO Box 7150
Tikipunga
Whangarei
New Zealand
Email: jscahill@ihug.co.uk
Telephone +64 9 437 6639
FAX: + 64 9 437 6601

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DBNZ International Conference

PO Box 7150

Tikipunga

Whangarei

New Zealand

Email: jscahill@ihug.co.uk

Telephone +64 9 437 6639

FAX: + 64 9 437 6601

4th Sense International Professional Development Programme for Professionals in the Deafblind Field

6 weeks in the UK

1 year follow-up project

Application deadline 31st March 2001

Sense International is pleased to announce details of its 4th Professional Development Programme (PDP). This will take place between 10th September and 19th October 2001.

The PDP provides professionals with the opportunity to:

- Increase knowledge and skills in a specialist area relating to sensory impairment
- Visit / observe different specialist services throughout the UK
- Discuss work and plans with professionals experienced in similar work
- Produce a project related to their work at home with the support of specialists in the UK.

Staff development is recognised as being an essential part in ensuring the development of sustainable services for deafblind people around the world. Hundreds of professionals have benefited from the opportunity of participating in international staff development programmes and their services offer proof of this. Past PDP participants have gone on to develop and improve their own services.

In the past Sense International has very much enjoyed the possibility of working with other INGOs and the PDP has proved to be an appropriate mechanism for doing this. If you feel that any of your project partners might benefit from participating in the PDP we would be delighted to hear from them.

Vimal Thawani was a participant on the PDP in 1997. On her return to India she ensured that her organisation, the Blind People's Association (in Ahmedabad, Gujarat) started a deafblind programme. Sense International has supported

this programme ever since and it is now one of the most successful services in Asia. It includes a specialist unit, with sensory stimulation room and audiometry service, and a community-based programme that reaches deafblind children in villages throughout the state. The programme is now so strong that the BPA itself is now supporting other organisations in Gujarat that want to work with deafblind children. The result is that hundreds of children and families are now able to access quality and appropriate services. As Vimal says "This would not have happened had I not been given the opportunity of participating in the Professional Development Programme."

For further information please contact:
Professional Development Programme
Sense International
11 – 13 Clifton Terrace
Finsbury Park
London N4 3SR
United Kingdom

Tel: 0044.20.7272.7774

Fax: 0044.20.7272.6012

Email: si@sense.org.uk



**Emanuela Brahamsha,
Senior Programmes
Manager for
Sense
International**

Management Committee News

The Management Committee met at Sense in London on 26th and 27th November with a very full agenda before them.

Mike Collins reported that DbI was in good shape! The growing activities around the world, with a conference planned for Africa to follow the very successful Asia event last year, campaigning in Brazil around schools policy and the increasing influence and memberships of Networks were indications that the organisation was moving forward.

Campaigning for separate recognition of Deafblindness

This issue, related to separate classification of deafblindness by the World Health Organisation (WHO), has been raised before and DbI has begun lobbying to make this a reality. Mike Collins reported that there had been no significant progress as yet, but, since it is a very important area, it could be a major campaigning issue for DbI members who could add their voices to apply pressure for a positive response.

Networks

William Green highlighted the fact that 10 Networks now exist, 2 are emerging and 3 are in the pipeline. The European Usher Syndrome Network was formally recognised by DbI. Many Networks are able to define their aims, but need some support to

achieve this. The financial security and general funding difficulties were discussed: no network is completely secure and the funding of members from low-income countries can be a barrier to participation. William is able to provide advice on applying for recognition, fundraising strategies, application procedures and general organisational considerations.

Strategic Planning

Strategic Planning is viewed as important to the development of DbI and consideration will be given to ways in which processes can be put in place. Marjaana Suosalmi introduced some principles in a presentation.

European Conference – the Netherlands 2001

Preparations for this conference are moving forward. The Scientific Committee has had a meeting to discuss the programme and to consider the abstracts that have been submitted already. The Networks are being encouraged to take the opportunity to meet in advance of the conference itself, but time will be allocated during the official dates too. The Dutch Planning Group are working hard to make everyone comfortable and to make this conference in the Netherlands a memorable experience.

The DbI Secretariat

The DbI Secretariat can be contacted c/o Sense International or by email: dbi@sense.org.uk

STOP PRESS

Would you like to arrange a holiday for European deafblind people in your country in 2002 and in the years to come?

EURO holidays have already been organised, with great success in the Czech Republic and France, and in 2001 the holiday will be held in Switzerland

Peter Vanhoutte and Jan Jakes are now looking for holiday destinations for the future and in particular 2002! They would love to hear from you if you think you could help to organise this rewarding event!

Please contact:

Peter Vanhoutte

Diestsesteenweg 33, 3010 LEUVEN, Belgium

Fax: 00 32 16 25 93 99

Email: peter-vanhoutte@pi.be

Jan Jakes

K vodojemu 29, 150 00 Praha 5,

Czech Republic

E-mail: jajakes@volny.cz

We will feature this in our next edition of DbI Review.



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 is free, but an annual donation of US\$30 is requested to cover costs.

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 make a donation of US\$30 ☐ or £20 ☐

I wish to make a donation of _____ (please specify)

Please debit my ☐ Visa ☐ American Express
☐ Mastercard

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Expiry Date

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

Please find enclosed my Postal Order ☐

Title (Mr., Mrs., Dr. etc.) _____

Surname _____

First name _____

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Post/Zip code _____

Country _____

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Fax: (please include country & area codes) _____

Email: _____

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: Deafblind International,
c/o 11-13 Clifton Terrace, Finsbury Park,
London N4 3SR, UK.

The following person is a member of DbI:

Name: _____

Address: _____

Signed: _____

Corporate Membership

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

Large corporates:

Annual fees between \$US3,000 and US\$5,000

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

☐ Bank Transfer

Name of Bank: RABOBANK

Address of Bank: Sint-Michielsgestel, Netherlands

Account Name: Instituut voor Doven: INZAKE DBI

Account Number: 11.29.09.825

Member Details:

Organisation _____

Representative _____

Address _____

Tel: (please include country & area codes) _____

Fax: (please include country & area codes) _____

Email: _____

Please return this form to: DbI Finance Officer,
c/o Instituut voor Doven, Theerestraat 42,
5271 GD Sint-Michielsgestel, The Netherlands.
(Fax: +31 73 55 12 157)