

DbI

Review

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INTERNATIONAL



Structuring the Environment

see pages 4 -14

A MESSAGE FROM THE PRESIDENT

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

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

The editor will be pleased to receive articles, news items, letters, notices of books and information on forthcoming events, such as conferences and courses, concerning 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 *Dbi*.

Dbi Review is also available in Spanish. If you are interested in receiving the Spanish edition please contact:

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This is the season when we tend to reflect on the past and look to the future: consider what we have achieved and our visions for the coming year. I have chosen to look to the future because the year 1999 is a highlight in the *Dbi* calendar, namely the year of the world conference.

Firstly, I would like to remind you that 1999 is the UN International Year of the Older Person. The theme of the year is "Adding Life to Years". During the past year, some countries have paid attention to people who develop dual sensory loss as a consequence of ageing. We know that at least 150 – very many more – out of 100,000 older people have a severe dual sensory loss. If an older person has difficulties in both seeing and hearing, in addition to all other functional and health



problems related to ageing, he or she can easily become isolated and lonely. I do hope that we all give a high priority to the UN initiative and raise the needs of older people with dual sensory loss. Even if many of these people do not belong to our traditional deafblind group, our experience of working with deafblind people will be beneficial.

The European region had a conference on older people. I was very pleased to see that many projects are going on in Europe, but of course, we need to do much more to disseminate

EDITORIAL

In this edition of *Dbi Review* we are focusing on **using the environment!**

We have articles from Finland, India and the UK which demonstrate approaches that are working for those concerned – but in very different contexts. However, the underlying philosophy is the same.

All the articles examine the meaning of the word "environment" and report a range of variables that amount to a whole lot more than just the physical world around us! Anni Lausvara

and Seija Troyano from Finland provide some interesting reflections on living and working with Usher, Meena Nikam introduces us to a family programme in India and Tony Best challenges our pre-conceptions and concentrates our minds on what constitutes "environments" from the child's point of view.

Since our last magazine, the first in the new format, we have continued to look at its design and have included in this edition a new section which will focus entirely on the activities of *Dbi Networks*. In the future we hope to include up-to-date information from

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information about these projects to people working in the deafblind field.

Many of us will be meeting in Estoril in Portugal next summer. Our colleagues at Casa Pia de Lisboa are busy planning and organising the conference. We have heard that many abstracts have been received, so we can expect a large amount of knowledge and experience on 'Developing Through Relations – Celebrating Achievements' to be shared between colleagues, families and deafblind people. In addition to the professional proceedings of the conference, our own General Assembly and Council meeting will take place. We hope the General Assembly will endorse the constitution and elect the first Council.

Networks are a very important part of our work – we could say that Dbl is a big network. Networks have their own area of interest and expertise which helps to

inform their work to other networks through networking. Let us together find new ways for our association to develop networks!

This edition of *Dbl Review* emphasises the environment and how we can affect the environment – both physical and social – so that deafblind people can really interact with their environment and be a true part of it. Most of our cultures are enjoying a celebratory season, let us adjust our ceremonial environments to be accessible for all deafblind people!

I take this opportunity to thank all of you who have actively worked towards the development of Dbl and wish this to continue in 1999.

I wish you all a good holiday season and a Happy New Year. By the way – Santa Claus lives in Finland. If you hear anybody arguing with this fact, they are definitely wrong!

Marjaana Suosalmi

each Network so that we can accurately reflect the issues under discussion and increase access for all of you who have a special interest. Since Networking has been identified by Dbl as a key area for the development of expertise, *Dbl Review* is looking forward to playing its part in supporting the process.

The Dbl website is developing well and we will be regularly posting up articles and information from our current magazine. We have an extensive back-catalogue of articles including the on-going series on causes of deafblindness. In addition, the work of the deafblind artists we featured in our last edition will be appearing in the new year. We hope that you will get the chance to visit us at:

<http://www.sense.org.uk/sense/html/dbi.htm>

Yet again, a big thank you to those of you who keep in regular touch. We enjoy hearing from you whether by e-mail or letter and because of your efforts we have been able to make sure that our regional news section really does reflect the work that is going on all round the world! Our intention is to include as many photographs as possible of activities and individuals – so keep clicking that camera!

It's a grey, cold December day here in London and already we're both looking forward to longer, warmer summer days and the World Conference in Lisbon. So see you there!

Eileen and Jacqueline

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Structuring the environment

In this article Dr Anthony Best, Headteacher of RNIB Condoval Hall School in the UK, argues the importance of understanding the environment for deafblind children. He examines the crucial elements and gives examples of practice that enhances learning.



Deafblindness creates a number of needs. One widely used definition describes these as needs in communication, mobility and learning. The main point of this article is that a structured environment can be the most helpful way of meeting these needs.

Structured environments can be achieved, at their very simplest, by careful arrangement of furniture. But this concept usually involves much more than that. The structure, or scaffolding, provides an environment that the child can understand – what is there; what is happening; and can interact successfully in it.

There are three well-recognised elements in an environment that need to be structured and controlled. These are people, space and time. This article is more concerned with the physical environment – space – but starts with an overview of the other two elements.

Environmental zones

Whatever aspect of the environment is being considered, experience leads many educators to identify a number of 'zones' that make

up a child's environment. One classification of these zones is to call them the face space, body space, personal space and social space. Each of these is concerned with a different sized area around the child.

At the very early stages of development, a child may be aware only of the face space – that area on and around his face; children bring their hands into that area, perhaps into the mouth and many objects are also brought up to this area. The next developmental stage may be when a child shows awareness and interest in their body (body space), and may respond to people touching them, or to objects placed on their body. Later the personal space around the child may be a source of interest with the child finding objects within a metre or so of them. They may be aware of other people near them and move their body through the space. Another developmental step takes the child into the social space, within two or three metres in which there will be a variety of people, objects and experiences.

As a child develops, these environments need to be structured so that, despite the

impairments to vision and hearing, they can be understood by the child. They will be a source of security, interest and learning, rather than simply providing a meaningless jumble of experiences.

People

In their early stages of development, it may be helpful if a child meets very few people, and a totally structured environment would limit the activities carried out by each person, so the child could build up an understanding, through consistency and repetition, of the environment. As the child develops, he can cope with more people and, perhaps, more variations in what each does.

A child may also be helped if adults make very clear who they are. Very young blind children are often confused when a person they recognise – for example their mother – changes from talking in their usual soft voice and becomes loud and angry. Without vision, the child may have difficulty understanding that this is the same person. In a structured environment, adults will control the way they present

Whatever aspect of the environment is being considered, experience leads many educators to identify a number of 'zones' that make up a child's environment.

themselves and make sure they give clear messages. They may, for example, use touch, a familiar routine or a personal 'sign' to help a child understand who is with them.

It may also be important to ensure clear messages are given through the spoken word. Without access to facial expressions and body language, children need the voice to carry emotion as well as meaning. Adults must listen to their voice to ensure it clearly conveys the emotion of the sentence.

Children may experience the person through touch. In a structured environment, the touch from the adult will carry a clear message. Adults must educate themselves to touch with meaning – conveying emotion such as affection, irritation, patience or pleasure in the way they touch – the pressure, duration, place, and speed.

If these elements are considered, then the environment should be meaningful, and can provide graded challenges appropriate to the child. If the people are consistent and reliable, then they should give a clear single message to the child. The degree of structure needs to be matched to, and change with, the development the child.

Personal identifiers, a form of objects of reference, are often used to help children identify a person. These objects, initially attached to the person, can be an important element in a structured environment. They can help the child be sure who a person is, act as a fixed point when the person's shape, clothes, smell or sound changes. Eventually they may be used separately from the person, to represent the person in, for example, a timetable. However, this



During this communicative exchange the child's attention is within his personal space zone

represents a later stage in development when much of the scaffolding can be removed and there is considerable flexibility in the environment.

Time

Structuring of time involves considering the order in which activities take place, and the organisation of events within an activity. In a highly structured environment, each element of an activity will be thought about, and the same sequence used each time the activity is carried out.

In early developmental stages, activities may be structured according to a developmental sequence of response. One such sequence based on McInnes & Treffry¹ is resonance, co-active, imitative and reactive. Each stage refers to the

child's understanding and response to the situation. For example, at the resonance stage the child's behaviour will be 'copied' by the adult who 'enters in' the child's activity; at the reactive stage the child responds to an approach in a way that shows some understanding of what is likely to happen. The next stage, and a crucial one in relation to the structuring of time, is anticipation.

Anticipation requires an understanding of a series of actions, or recognition of a series of sequential elements in the environment. For example, that the smell of a fruit is followed by the taste in the mouth; that a sequence of touches on the hand and arm is followed by a tickle; that touching several pieces of familiar furniture will be followed by arriving at another piece. Structuring the environment in terms of time,

Anticipation requires an understanding of a series of actions, or recognition of a series of sequential elements in the environment.



An experimental system of objects of reference used to signpost journeys

should help children develop the skill of anticipation.

Very much of our understanding of our world – what is happening, what is stable, a feeling of familiarity – comes from the ability to anticipate through recognising a sequence of events. When this skill has emerged, educators can use it to help the child develop further skills, particularly in communication and problem solving. This uses a teaching technique found widely in the field of learning difficulties but which was probably first developed for use with deafblind children at Sint-Michielsgestel. It is mismatch.

When a child is familiar

with a sequence of events within an activity, then the teacher can delay one element in the sequence by introducing a pause. The child may then attempt to have the sequence continue, for example by reaching for the adult's hand or giving some indication of frustration. At this stage, there is the opportunity to use this response to introduce an action that the child can make to have the sequence continue. This action becomes a sign, perhaps meaning 'please continue', 'I want more' or even 'I want the next action'. With mismatch, the adult may also change an element in the sequence, hoping the child will notice the change and try to find a way to restore the original order of events.

It is suggested, therefore, that structuring the environment in terms of time might help learning. However, it is not suggested that all activities must be organised in this way. Spontaneous and unstructured activities, led by the child may also be a rich source of learning experiences. A balanced educational programme will include both types of activities.

Space

Structuring spaces should help a deafblind child recognise familiar places, and understand that places have purposes. The journey a child makes through a space whenever they move is potentially an important learning experience. Here it is suggested that the concept of learning journeys can be used in planning an educational programme.

Research over the past 30 years, and most notably the

recent work of Neilsen,^{2,3} has found that smaller spaces are usually better for multi-handicapped children. A space as little as 60 cm square may sound, and feel, manageable to a child. It enables them to touch the walls, floor and ceiling and build up a mental image – a spatial map – of the space. One can imagine how undefined a normal-sized room might seem to a deafblind child, unable to experience any more than one small part at a time.

It seems necessary to have some sort of spatial map of an area in order to understand – be orientated – to it. This understanding is probably necessary before a person can move through the space. Of course, the nature of the map may not be visual. In fact, blind people sometimes talk of memorising a sequential series of experiences that build up into a 'picture' of a room. However the concept is internalised, and recalled, it does seem likely that smaller spaces are an important starting point for developing the skill of spatial mapping.

The 'little room' that Neilsen has written about provides a good starting point. Using panels that make up rooms with walls of 30, 60 or 90cms, the child can be given experiences of different sizes and textures through combinations of panels. Children observed in these little rooms often seem to move and explore more than when observed in large rooms. It is likely that, whenever they stretch out a hand, they will touch something on a wall or ceiling. With repetition they can build up an image of the space they are in and learn to anticipate what they will touch.

Without vision, there may be no fixed point, such as is provided for sighted people when they view the world from the eyes in their head. For us, it is simple to understand that when we move around a room, we see it from a different position but the furniture stays fixed. However, we know that this can create a problem for some very young blind children. They may not realise, for example, that when they roll over onto their tummy, the floor does not come up to meet them, but it stays still while they are moving. A deafblind child, therefore, may not realise that if they roll over from one side to another and reach out, the object they touch is one that was previously behind them! Only with structured experiences of a stable, small physical environment, is this understanding likely to develop.

It is possible to provide cues within a physical space that will help a child develop their understanding. Some of these cues will be tactile. In particular, tactile edges can be very useful. These may be a well-defined edge between walls and floor, floor covering in different parts of a room, the floor edge between a room and corridor, wall covering to differentiate different parts of a corridor. In general, the contrast between each side of the edge is the most important element to think about. For example, a carpet and linoleum floor provide a good tactile contrast; hessian and paint wall covering give a good contrast.

Some of the tactile cues will come to be associated with a specific area. For example, in a classroom the area with a hard linoleum

A deafblind child, therefore, may not realise that if they roll over from one side to another and reach out, the object they touch is one that was previously behind them!

floor could be where there is water. Through familiarity, the child will build up an understanding of the space – a skill in *orientation*. They will also need to develop the skill of *mobility* – of moving through the space. Some of the cues will therefore be used as hand or foot clues in mobility. For example, a child may follow a wooden handrail along a corridor until they come to a marker that indicates a doorway; they may follow the edge of a carpet with their feet to find their way to a bookcase or chair.

In providing tactile cues, it may be worth remembering that open spaces will be the most difficult areas to understand, and to move through. If there are no fixed points that can be seen or heard, it is difficult to judge the size and shape of a space. They present a much greater challenge to the learner than spaces with walls, furniture and tactile markers. For children in wheelchairs, open spaces are particularly difficult. Children may equate the time taken to move through an area with the size of the area and so the speed of moving is very important to control. Adults sensitive to this can structure

the tactile environment, through their behaviour and through organising furniture, to help children understand and use it.

Many deafblind children have some vision and are helped by visual cues in the environment. Again edges are important, and these can be achieved by colour contrast. Lighting levels need to be carefully controlled as too much, or too little light can prevent a child using their vision. It is particularly important to control glare as children with impaired vision may find a small degree of glare is very disabling.

The sound environment will be important to children who can hear. Edges will provide information that helps to give shape to a space. Sound edges are achieved through furniture that creates sound shadows. For example a bookcase dividing a room will create a partial barrier to sound. When the child moves past the bookcase, the 'shadow' will be removed and sounds from behind it will be much clearer. This should help a child orientate themselves to the space. As well as furniture, doors, windows, hedges, walls can all create sound shadows that may be helpful to a child



A tactile space: the deafblind child's experience is focused on the hands and clay

without vision.

The sound environment will probably have some fixed points – sound sources that can be used by children to orientate themselves. A ticking clock, traffic outside a window, radio, fish tank, wind chime may all provide a sound cue that children can learn to use. An interesting sound environment will have variety in it, in the same way that as a good visual environment will have a range of colours, pictures and focal points. Sound variety can be provided in zones within a space but also over time, with periods of quiet, noise, speech and music introduced into the daily routine.

Each of these elements in the physical environment can be organised to give support to a child and thought given to the tactile, visual and sound elements will have a significant impact on the challenge that any space presents to a child.

Learning Journeys

The degree of structure that is required in an environment may be determined by the needs of the child and his learning goals. But there are many occasions when a child moves through a space and each time there is the potential for learning experiences. In order to identify these potential experiences, each journey the child makes can be considered a learning journey. This concept, a central part of the philosophy of Conductive Education, can apply to any journey, however small. For example the route from a child's chair to the door, from the bathroom door to a sink, from

In order to identify these potential experiences, each journey the child makes can be considered a learning journey.

the classroom to the school entrance, from the sitting room to the child's bedroom, between buildings on the school campus, through a shopping centre.

As sensory impairment creates severe challenges to understanding spaces, an examination of each learning journey will identify opportunities to develop mobility skills, to enable the child to find their way along the route. But there are many more opportunities than that. There is the possibility to develop an understanding of distance and time; there may be the opportunity to practice skills in sharing, taking turns, choosing, helping other children; there may be communication opportunities with requests, choices, anticipation, generalisation or practising familiar words.

If the concept of learning journeys is included in the delivery of individual

educational programmes, then structuring the environment becomes an essential part of educational planning. People, space and time can form the scaffolding within an environment that enables learning journeys to take place.

In order to help identify the learning opportunities within an environment, another concept, the ecological audit, can be used.

Here, the ecological audit is defined as an examination of what happens within an environment and identification of the skills needed to function effectively with those activities. An excellent guidebook on this has been produced by ICEVI/ Bartimeus.⁴

It uses the concept of environments and sub-environments. An area – such as a house – can be considered as an environment. Many activities



Structuring space: an adult becomes part of the play space

will take place within it, and it is usually possible to identify sub-environments within the house where a more limited range of activities occur. For example, the kitchen, bathroom or bedroom. Even a sub-environment such as a bedroom will have different areas, each forming another sub-environment. The bed area will be where a child goes to sleep or makes the bed. To carry out each of the activities specific skills will be required.

Another sub-environment will be the wardrobe (cupboard or closet). It is possible to identify the activities that will be carried out here – such as locating clothes to put on. The skills needed to carry out this activity can be identified, although these will depend on the degree of environmental structuring. For example the order in which clothes are hung on clothes hangers, or arranged in sections on the rail; the use of different shelves for different types of clothes items; the system used for labelling clothes of different types or colours.

When the skills needed to carry out the activity have been listed, a child can be assessed at the task and the results used to formulate a learning programme. Clearly the degree of structure in the environment will affect the skills needed by a child, and the task can be made easier or more difficult by the degree of structuring. This example has focused on the physical environment but it is possible to include the people and time elements in a complete ecological audit.

The ecological audit enables staff to analyse the situation precisely. It can help identify the skills needed by the child and the significant



Building mental maps of spaces: the mattress helps give shape to the sheet

elements that are in the environment that can be changed. This information can be used to structure the environment and so helps to provide a good learning environment for a child.

Conclusions

In this article it has been argued that one of the most severe privations created by deafblindness is in understanding the environment. By structuring the crucial elements of people, space and time, an environment can be created that will facilitate learning. An ecological audit of environments and sub-environments will identify the skills needed by children to function in the environment. This information should lead to greater precision in learning programmes and, hopefully, enhanced learning by children.

- 1 McInnes J M, Treffry J (1982). *Deaf/Blind Infants and Children* University of Toronto Press, Canada.
- 2 Neilsen L (1988). *Spatial Relations in /Congenitally Blind Infants*, Refsnaesskolen, Denmark.
- 3 Neilsen L (1992). *Space and Self*, Sikon, Denmark.
- 4 Zambone A, de Jong C (1997). *The ICEVI-Bartimeus Model Functional Curricula*, Bartimeus School, The Netherlands.

Changing spaces: developing an accessible workplace

This collaborative article has been written by Seija Troyano, who has Usher Syndrome III, and Anni Lausvaara who is head of a national employment project for deafblind people. In the sections printed bold, Seija talks about her personal experiences of the physical environments at her workplace, which is a Day Care Centre, and her home. Anni supplements Seija's account with her experience in supporting people with Usher in their occupational environments.

I have some experience of changing the living environment to make it more suitable for a deafblind person.

The importance of the physical environment for a deafblind person at work is crucial. At its worst background noise and visual difficulties may demand so much energy, that the deafblind person has few resources left to successfully use his professional skills to do the job! Whereas a well-functioning environment makes it possible for a deafblind person to succeed in a placement.

In this article, we aim to discuss the optimal functional level of one workplace with the help of examples.

Lighting

The day care centre in which I work has a clear structure. This is very important in terms of mobility and sight to how I cope in that environment. The six departments are on two floors. There is an open garden in the middle of the building with a swimming pool, fire place, sand box and many plants. There is a lot of light especially in the garden, which is covered by a glass

roof. In my opinion the lighting at my workplace is relatively good. It is in the form of fluorescent tubes, which can be switched on and off to suit one's needs. I have seen much darker workplaces than this!

Even, overall lighting creates a pleasant occupational environment for a person with Retinitis Pigmentosa. As a general rule lights should be around 300 – 500 lux. Lighting levels under 200 lux makes the premises dim and anything under 50 lux is experienced as darkness. Additional lights are needed at work stations. It has to be remembered that there should not be too great a difference between lighting at a work station and overall lighting, since the eyes are slow to adapt to any changes in the lighting level (Seppälä 1993). Brighter lighting than overall lighting can be used for emphasising differences in levels in the physical environment.

I have some experience of changing the living environment to make it more suitable for a deafblind

person. Before I moved in the whole building was renovated and lights, colours, contrasts, doors, cupboards etc. were planned with the help of an architect and a lighting specialist from the central hospital. Now there is effective lighting especially in the kitchen, living room and hall. Also, the sauna has proper lighting! The result is very satisfactory. At the same time the whole building was fitted with better lighting in corridors, elevators and other common areas. This benefits other residents as well!

Indirect lighting is optimal for an Usher person. The light is reflected from the source via wall or ceiling so that it does not get directly in the eyes causing dazzle. Indirect light also brings out the contrasts more successfully, which makes it easier to orientate oneself. Indirect light is not reflected from shiny surfaces to the same extent as direct light, which is a remarkable benefit.

When locating individual lamps at the day care centre, the storerooms (both interna!

and external) should be included. It is most important to place the lights so that they are not at eye level and that the light does not directly dazzle the eyes.

The use of natural light must be considered in lighting plans. Day light gives a great output of light, but direct sunshine from the windows is very dazzling. It is a good solution to use blinds, since the light direction can be turned up or down.

Because retinal degeneration delays the eye's capacity to adapt to different lighting levels, it is important to pay attention to lighting in the yard and at the entrance. The day care personnel take the children out to play once or twice a day. In the Nordic latitudes the lighting outside varies depending on the season, from total darkness to bright sunshine with sparkling snow

banks! Coming inside from the daylight may make the hall seem totally dark and unsafe. The evening twilight causes similar problems of dazzle. An optimal solution would be an entrance light which reacts to the power of natural light to compensate for the gradual change from daylight to twilight (Jokiniemi 1998). Proper outside lighting gives support in transitional situations. The amount of light has to be adequate and more efficient mercury vapour lamps can be used instead of incandescent lamps (Seppälä 1993).

Use of colours and contrasts

Usher Syndrome also means a lower contrast sensitivity i.e. lower contrast differentiation. The visual system's capacity to

distinguish luminance differences or darkness differences between surfaces beside each other becomes weaker.

I have been working at the day care centre for ten years. During that time some renovations have been made, the most useful of which is an improvement in contrasts. The yard is clearly structured and the plants and the trees around make the contrasts even clearer.

At my home, the doors and thresholds have laths in different colours, which make it easier to orientate oneself. The 15-floor building has contrasts in stairways as well. The contrasts are clear but discrete. These kinds of solutions are equally suitable for the rest of the residents who have no visual difficulties.

The yard is clearly structured and the plants and the trees around make the contrasts even clearer.



Most important for floor, wall and ceiling areas is simple colouring. The floors may well have a little darker colour than the walls and the ceilings, because more light falls on a horizontal surface. Light colours are recommended on surface materials, because in large areas dark surfaces may absorb too much light (Jokiniemi 1998). On the other hand pure white large surfaces may have a dazzling effect.

◀ **A general view of the corridor at the Residential Activity Centre for the Deafblind. In the high space there are two kinds of lights in order to create sufficient light and a cosy environment. Natural light enters the room from the right hand side of the ceiling. The sign on the back wall is illuminated with a spot light with a glare shield. Notice the dark contrast stripes on the light wall. The ceiling is covered by acoustic plates. In addition, the wall on the right hand side is covered with a perforated wooden plate which fades out the echo.**

Patterning on the floor may disturb the orientation, whereas clear stripes on the floor may function as a guide to an exit or stair way. For safety reasons it is necessary to use cross-stripes as markers of changes in level (Verde 1996).

Acoustics

The only disadvantage at my working place is the echo. It is emphasised especially by the children and at the moment there are 23 of them! For instance, when all the children are putting on clothes at the same time I would like to turn off my hearing aid!

Excessive background noise and echoes make the environment unbearable for hearing aid users. The acoustics have to be improved and usually around 30 – 50% of the ceiling area should be covered with an acoustic material. In the same way one or two walls should be treated over one third of their surfaces. Industrial machines and clattering dishes in the kitchen demand that at least the ceiling should be made acoustically friendly. The doors should be tight.

Also long thick curtains and wall textiles, carpets and bookshelves damp the echo. Table and chair legs that are likely to rattle can be equipped with sound damping material like felt or pieces of wall-to-wall carpet. In addition, the inlets of air conditioners should be provided with a damping cover.

I am already on good terms with the echo, and, when needed, I remind the children that they can manage even with less volume! The fact that I occasionally make these remarks pleases my colleagues and their ears!

The most important factor which influences the background noise at the day care centre are the children's voices. The noise level is measured between 76 and 84 decibels (Helsingin Sanomat 1997). The results are alarmingly high, not only for a hearing aid user but also for anyone else.

An effective way to decrease noise is to encourage the children's understanding of the effects of noise on a person with dual sensory impairment. For instance, the children can hear how the voices sound when amplified by

experiencing a hearing aid themselves. Also a narrow visual field can be simply simulated by seeing the world through a hole in the paper.

Finally

Every autumn there are new children in our pre-school class. I feel it is important to describe my situation at the parents' evening and to tell them about my hearing and sight. Knowledge makes things easier with fewer misunderstandings.

In addition to the workplace's physical environment the social environment is of equal importance. It is the deafblind person who is the expert on how to get communication to work. These information skills are worth practising and improving.

Sources

Helsingin Sanomat 16.9.1997: Päiväkotien suurista ryhmistä lähtee vaarallisen paljon melua. (Big day care groups make alarming amount of noise).

Jokiniemi, J (1998): Toimiva ympäristö jokaiselle. Heikkonäköiset henkilöt arvioimassa rakennettua ympäristöä. (Working environment for everyone. Visually impaired persons estimating the constructed environment). Published by Helsinki University of Technology, architectural faculty 1998/48.

Seppälä, J (1993): Valaistuksen vaikutus heikkonäköisen toimintakykyyn. (Purpose of lighting for the functional capacity of a visually impaired person). The Central Federation for the Visually Handicapped.

Verhe I (1996): Selkeä ympäristö. (Clear environment). Helsinki. Published by Rakennusalan kustantaja RAK and The Central Federation for the Visually Handicapped.

The garden at the Residential Activity Centre for the Deafblind. In planning the yard the use of contrasts has been focused on in terms of vegetation and the constructed environment. The scent of plants and the various surface materials guide the deafblind person's orientation in the environment.



A natural setting for learning – the home

Meena Nikam, Special Educator, National Association for the Blind, Mumbai, India, reports on the newly developed home-based programme which involves families and children in the creation of a learning "environment" for those who are unable to access schools and formal educational provision.

"Every child has a right to be educated. He is entitled to garner knowledge at his own pace and to the best of his ability".

How can we make this laudable intention a reality?

After attending a nursery for the blind for two years, Sumitra, a deafblind child with hypotonic muscle tone remained at home. Her parents found it difficult to carry her to the only school, 35km away because the local trains were overcrowded. Alok and Vishal, children with visual and additional disabilities, were forced to stay home for the same reason. The parents of Kaushik and Gurmit tried their level best to enrol their children in the special schools, but their requests were turned down due to the combination of their disabling conditions. Prameed, Mukesh and Pratik have never been to any school as there are



Mumbai families at the beach

none in their neighbourhood.

In India, due to advances in medical science, there seems to be an increase in the survival rate of children who have multiple disabilities. At present, only a few schools have provision to cater for these children. In the year 1995, the National Association for the Blind, India, started a service programme for children with visual and additional disabilities in the City of Mumbai and its suburbs. It is a family centred, home-based programme, specially for children who can not attend school or any day-care centre

for various reasons, such as lack of suitable transportation, a child's physical and mental health, the socio-economic status of the family or a lack of appropriate services. At present this programme serves 35 children and their families.

Each family is involved in the planning, decision making, implementation and evaluation of the programme. All parents, even those with minimum education, learn sufficient skills and are able to carry out the programme in the most natural setting.

It is a family centred, home-based programme, specially for children who can not attend school or any day-care centre for various reasons

With family support, it also becomes much easier to involve other members of the family and the neighbours. The families involved are a diverse group. Differences of culture, education, language, economic and social status do exist and the NAB Service faces the challenges related to them. Most of the families have financial concerns, and as a result parents are generally unable to spend money on educational toys, assisting devices, or visits to a therapist. They live in small houses. They have very little time at their disposal to attend to their disabled child on account of their involvement in day-to-day family responsibilities. All these limitations develop stress in the family. Hence a good deal of understanding and flexibility in one's approach is imperative while working with these families.

However, the families and NAB staff find ways around these difficulties.

Saili lives in a very small house, where there is hardly any space to move around let alone play. To enhance her mobility skills, a special teacher has to take her out to a public garden or a beach.

Instead of spending money on expensive equipment like a standing frame, working table, special chair and splints, Swapnali's father chose to make these things at home under the guidance of a special educator. Certainly, he has done a wonderful job!

The specially made sensory room, relaxation room, hydrotherapy pool, are either not easily available or are absent. So, the use of public gardens, gymnasiums or swimming pools compensates for this. It also helps in changing attitudes of family and society towards



Swapnali uses her equipment

these children.

The aim of our service programme is to help families to equip themselves with skills they need to deal with ongoing challenges. The success achieved so far is evident through the progress of children and change in attitudes of families and their neighbourhood communities.

During the last three years, out of our 35 children, we have been able to enrol 12 children in normal schools. Also, three special schools

for mentally retarded children, have sought our assistance in an advisory capacity.

The progress of these children, during a comparatively short time is very encouraging. "Progress generates progress". More and more families have shown increasing interest in the development of their children and there are smiles all round at the small, but significant, steps the children are making!



The Management Committee recently met on 20 – 22 November in

Noordwijkerhout in the Netherlands. Many matters regarding the development of Dbl were discussed including network development and membership drives.

The highlight of the meeting was the presentation by the Conference Planning Committee about the preparations to date for the 5th Dbl European Deafblind Conference to be held in the Netherlands in July 2001. The Management Committee were able to tour the Conference venue and suggestions were made to ensure maximum accessibility for all participants. We are pleased to

announce that deafblind colleagues will actively participate in making the venue accessible. The theme of the Conference is still being discussed and no doubt members will soon hear about the Conference. The Management Committee are very excited about the progress to date.

Final preparations are now being made for the XII World Conference in July 1999 in Lisbon, Portugal. A new Council for Dbl will be elected at the General Assembly to be held during the conference. Details will be included in the final announcement. We hope that you will all be able to attend and have your voices heard.

Dbl is pleased to announce the creation of a small sponsorship fund to help support colleagues from developing countries to attend Dbl's international conferences. The fund will be available for Dbl's forthcoming XII World Conference in Lisbon in July 1999. Those interested in applying should write directly to Rodney Clark outlining clear arguments in support of their application. Priority will be given to individuals in leadership positions within deafblind services and those wanting to give presentations.
**Rodney Clark, Dbl Secretariat,
11-13 Clifton Terrace, London N4
3SR, United Kingdom.**

CALL FOR PAPERS and CONFERENCE ANNOUNCEMENT
Casa Pia de Lisboa invite you to attend

XII Dbl World Conference

20 – 25 July 1999

Developing through Relationships – Celebrating Achievement



Programme

- Relationships between congenitally deafblind children and young adults and hearing sighted people
- Relationships between/among deafblind people
- Relationships between families and professionals
- Relationships across borders.

The Theme will be developed through plenary sessions and workshops. There will also be a Network Day for Dbl Networks.

Venue: Centro Escolar Turistico e Hoteleiro, Estoril, Portugal

The centre is in a resort 20kms from Lisbon and is accessible by wheelchair users.

Official Languages: The official languages will be Portuguese and English, and translation will be provided into these two languages. Other interpretation needs should be organised by national groups.

Call for papers: Delegates are invited to send an abstract, about ten to fifteen lines long. The Programme Committee will give priority to Papers that directly relate to the Conference theme, however papers addressing other issues will be considered. Dbl Networks are invited to present a programme proposal for the Network Day

FINAL DATE FOR PAPERS AND NETWORK PROPOSALS – 28TH FEBRUARY 1999



To XII World Conference of Dbl, Planning Committee, Casa Pia de Lisboa/CAACF,
Av do Restolo 1, 1400 Lisboa, PORTUGAL.
email: cpl.educa@mail.telepac.pt
Tel: + 351.1.362 71 35 Fax: + 351.1.363 34 48

ALL CONFERENCE ENQUIRIES TO THE ABOVE ADDRESS

Networks

ACQUIRED DEAF/BLINDNESS NETWORK

c/o Annalee Souter
Stichting Doorbinder
c/o Stichting
Dienverleners
Gehoorlozen
Christine Krommelen 2
3571 AX Utrecht
THE NETHERLANDS
Tel: +31 - 30 -
276 9970/0489
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271 2892

COMMUNICATION NETWORK

c/o Jacques Souto
L'Habit d'Or
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86380 Vandœuvre 4
FRANCE
Tel: +33 - 5 -
49 52 09 24
Email: souto@nttppc.fr

CONGENITAL DEAFBLINDNESS IN ADULTS NETWORK

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420 1778
Fax: +44 - 192 -
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Email:
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EUCO UNIT/STAFF DEVELOPMENT NETWORK

c/o Lieve de leuw
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Theoriepoort 42
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Email:
iSDinternational@td.nl

EUROPEAN USHER SYNDROME STUDY GROUP (EUSSG)

c/o Mary Guest
Sense
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272 7774
Fax: +44 - 171 -
272 6012
Email:
MGuest@tames.org.uk

In the last edition of *DbI Review* we reported on Dbl's Interim Council's decision that networks can be recognised as soon as they are established on the proviso they meet the criteria set by Dbl. There are many networks currently involved within the deafblind field but are not currently recognised by Dbl. If you would like your network to formally become part of Dbl then please contact the Dbl

Secretariat.

In this edition of *DbI Review* we have introduced a new section called **Network News**. This part of the magazine gives Networks the opportunity to report on their activities, share information with fellow Dbl members and consult a wider audience on specific issues. In this edition, Mary Guest reports on the formation and priorities of the European Usher

Syndrome Study Group and the Communication Network have provided details of their forthcoming course **Development of Communication in Persons with Congenital Deafblindness (Part 2)** to be held in April 1999 in Paris, France. We have also included contact details of the five existing networks affiliated to Dbl. We look forward to receiving more Network News in the future!

European Usher Syndrome Study Group

Since the beginning of the European Usher Syndrome Study Group in 1985 we have observed a marked improvement in awareness for and recognition of Usher Syndrome in many European countries. This greater recognition is welcome because it means that people with Usher can begin to voice their needs and campaign for better services.

It was also recognised in Madrid, at Dbl's 1997 European Conference, that there was a need to develop a network for people with Usher and their families; who could establish links with each other, reach out to new families and, through these links, start to improve services in their own countries. A small steering group was therefore formed made up of representatives from Spain, Denmark, Germany and the UK with the job of putting together the aims and objectives for the



Mary Guest, Hans Jürgen Krug and members of EUSSG in Madrid 1997

new European Usher Network.

This steering group have met twice since 1997, in Denmark and Germany. A third meeting is planned in the Autumn of 1999 - we hope in the UK. We want to tie it in with other meetings which are likely to attract professionals in the field of vision and hearing to save costs. In the meantime we have put in a bid for financial

support from the European Union, the results of which will influence the next phase of activity.

It is early days for the Network, but we hope it will mark the start of a movement of people with Usher and their families to get better recognition throughout Europe.

Mary Guest
Secretary EUSSG

SECOND ANNOUNCEMENT: Development of Communication in Persons with Congenital Deafblindness (Part 2)

10-14 April 1999

This course is reflecting the ongoing process of developing communication between persons who are deafblind and their seeing and hearing partners. In 1996, Part 1 focused on interactive aspects of communicative development. Part 2 will look at co-construction of shared meanings and negotiating first vocabularies.

There will be a pre-course day on 10 April 1999 to allow those who missed the first part of this course and for those who would like to review it, to feel comfortable with the second part. The presentation of the course will take place at CNEFEI, 58-60 Avenue des Landes, 92150 Suresnes, Paris on 11 April to 14 April 1999. The course aims to allow professionals and families to build adapted means of observation and intervention with congenital deafblind persons in language and communication.

Programme

Friday 9 April 1999

Arrival of participants of the pre-course

Saturday 10 April 1999

9.00-17.00 This pre-course day will be a short review of the main topics covered in Part 1 and will be led by Anne Nafstad, Inger Rodbrøe and Marlene Daelman.

Arrival of the participants of the course.

19.00 Welcome party

Sunday 11 April 1999

10.00 Official welcome
 10.30-12.00 Keynote speech by Jacques Souriau and presentation of film
 14.00-15.30 Plenary '*The concept of natural language. What does this mean for Congenitally Deafblind People?*' by Arnfin Vonen, University of Oslo.
 16.00-17.30 Workshops

Monday 12 April 1999

9.00-10.30 Plenary '*Event representations*' by Katherine Nelson, City University of New York.
 11.00-12.30 Workshops
 14.00-15.30 Plenary '*Narratives*' by Colwyn Trevarthen, University of Edinburgh.
 16.00-17.30 Workshops

Tuesday 13 April 1999

9.00-10.30 Plenary '*Detection of and expectation for social contingency: their contribution to communicative development*' by Jacqueline Nadel, Centre National de la Recherche Scientifique, Paris.
 11.00-12.30 Workshops
 14.00-15.30 Plenary '*Pragmatics*' by Pamela Rollins, University of Texas, Dallas.
 15.30 Excursion

Wednesday 14 April 1998

9.00-10.30 Plenary '*Co-constructing shared meaning and negotiating first vocabularies*' by members of the Working Group on Communication; Marlene Daelman, Inger Rodbrøe, Ton Visser, Anne Nafstad and Jacques Souriau.
 11.00-12.30 Workshops
 14.00-15.30 Plenary '*Parent witnesses*' by Norman Brown, University of Birmingham, UK
 16.00-16.30 Plenary '*Conclusions*' by Dr Anthony Best, Headteacher, RNIB Conover Hall School, UK
 16.30-17.00 Closing Ceremony
 19.00 Closing Reception

Workshops will be facilitated by members of the Working Group on Communications and will focus on the plenary topics. Each workshop leader will have the opportunity to work with colleagues in the preparation and presentation of workshops.

For further details and an application form please contact: CNEFEI, 58-60 Avenue des Landes, 92150 Suresnes, Paris, France. tel: + 33 1 41 44 3100 fax: + 33 1 45 06 3993

Employment for deafblind people

In the December 1997 issue of *Deafblind Education* there was a focus on *Employment*. Richard Hawkes, Transnational Co-ordinator of a major European initiative aimed at developing employment possibilities for deafblind people, outlines developments since then.

In less than a year tremendous steps towards the creation of real jobs have been taken in a number of countries. In the European Union funded Horizon project, the partners from Italy, Portugal, Sweden and the UK have had a number of meetings to discuss developments in each country and undertake joint work on the production of international guidelines.

One of the main issues to arise from these meetings has been the concept of challenging attitudes if real progress is ever to be made for deafblind people to have a genuine possibility of getting jobs. This means challenging the attitudes of employers, society and, most importantly, those of us within the deafblind world. The Horizon Group recognise that there are many excellent services for deafblind people throughout the world, but very often the attitudes of service providers are dominated by feelings of "providing services or care" as opposed to "creating opportunities" or "encouraging independence". If work opportunities for



deafblind people are ever to be a reality these attitudes must develop and those within the deafblind field have to genuinely believe that employment opportunities and greater independence are possible.

To start achieving this, consideration is being given to the creation of an Employment Network within Dbl. This whole subject will be discussed in more detail at the Employment Day at the World Conference in Portugal next July.

In the UK Sense West recently organised a major conference on employment issues for sensory impaired

people. More than 100 people attended this event which, over two days, received presentations from Richard Howitt MEP, a representative from the UK Government and speakers from employment and disability organisations. It is very promising that this issue has been brought to the attention of governments, MEPs, the European Commission, and with the continued support of such individuals and organisations, everyone involved in these projects is confident that substantial progress will continue to be made.



Objects of reference: an exploratory meeting

What do we know about why objects of reference work? What is their role in relation to other approaches to communication? What are the priorities for research into the use of objects of reference? How can objects be used most successfully?

An exploratory meeting was held in June 1998 to examine the current use of objects of reference in order to compile a research/issues menu. That menu, based on what we do not know, would suggest useful development activities that could help the field move forward.

The programme was arranged as a series of

stimulus papers and each participant was invited to talk about their work, give examples from their practice, challenge thinking and identify gaps in current knowledge.

During the meeting, the choice of objects, the way in which they are used and how transition from objects to other forms of communication are initiated were all discussed in depth. In addition, a review of the literature was presented and the relevance of both staff development and research were considered.

The meeting was held at RNIB Condoover Hall School over a weekend with

colleagues from Europe and USA. The meeting was accomplished and a menu of possible areas for future work and action was established. This was a very tentative initiative in a relatively unexplored area, but participants hoped the result might provide a starting point for anyone wanting to contribute to the development of our knowledge.

A summary report of the meeting is available from Sense or RNIB Condoover Hall School.

Anthony Best
Eileen Boothroyd

POSCAL

POSCAL is supported by FSDB, the Swedish Deafblind Association and SHIA, the Swedish Organisation of Handicapped Aid Foundation. It's president is Yolanda de Rodriguez, a Colombian who is herself deafblind and physically disabled.

POSCAL was founded in February 1995 in the "Andean" countries: Bolivia, Colombia, Ecuador, Peru and Venezuela. Since September 1997, with the generous support of FSDB, SHIA, ONCE, the National Organisation for the Blind in Spain, and ULAC, the Latin-American Union for the Blind, it has grown to include ten more countries in the region. These are Argentina,

Brazil, Chile, Cuba, the Dominican Republic, Honduras, Guatemala, Nicaragua, Mexico, and Uruguay.

By July 1998, associations for deafblind people have been established in six of the countries supported by POSCAL. Each of these organisations has been given a computer, a Braille printer and training to support their activities.

POSCAL produces a quarterly newsletter giving news on deafblind adults living in the region. It is available in English and Spanish and is for sponsors and others who are interested in the work of POSCAL. A Seminar is also organised each year. This

is an important annual meeting enabling the exchanging of ideas and experiences, and planning of future activities.

Each country supported by POSCAL also receives a moderate contribution to finance their national work and to assist with communication between countries. In Colombia, POSCAL also supports the deafblind training module for interpreters for the deaf and the deafblind.

The project has awakened interest in many places and so far, in fifteen countries across Latin America, around 1,300 deafblind adults and children have been identified! POSCAL's supporters and funders are very proud of the results.



Ximena Serpa is Co-ordinator of POSCAL, a project created to support the development of deafblind associations in Latin America. Ximena reports on the background to and the worth of POSCAL.

**MALAYSIA**

Rodney Clark writes about his visit to Malaysia and meeting the pupils and staff of the Deafblind Unit at St Nicholas' Home in Penang, which has been in operation since January 1997.

Nothing can prepare you for the tropical lushness and riches of Malaysia. Even in monsoon weather the bright colours of the exotic vegetation, animals and birds shine through. Driving through the country we passed through banana and oil-palm groves, rubber plantations and rice paddies, and everywhere we went we received a warm welcome.

St. Nicholas' Home began life in 1926 to serve "eight crippled and blind children." It was opened by the Singapore Anglican Diocese in a hospital compound in Malacca. In 1931 it moved to Penang and its present site and buildings date from 1938. A kindergarten for 28 blind children was started in 1941 and by 1959 the roll of primary-aged children had risen to 74. The integration of secondary-aged blind children into ordinary schools began in 1960 and became official government policy two years later. From 1964, the Home developed a wide range of different services for blind and visually impaired children and adults. In 1997, the primary school, which was wholly sponsored by the Malaysian government, moved from the St Nicholas' Home site to the mainland.

The Home now runs a number of Community-Based Rehabilitation programmes covering Penang and the Northern Malaysian states of Kangar, Kedah and North Perak. These include Early Intervention; Rehabilitation for Blind People in rural areas; and a Multi-



Handicapped programme; with teachers from the Home supporting locally-based field workers.

The Deafblind Unit currently has 6 children aged 10-14. It is located in 2 large, colourful, airy rooms; one for education and one for physiotherapy. It opened with financial support from the Hilton Perkins International Programme, who have offered a range of training possibilities. These include trainers visiting on site, staff participation in short courses in Surabaya (Indonesia) and in Boston, and staff placements at the Helen Keller Institute in Bombay.

Most of the children attending the unit were identified through the Multi-Handicapped CBR programme and their disabilities mostly result from Congenital Rubella, despite Malaysia's successful immunisation programme which has run for many years. It was the school holidays, so I visited 5 of the 6 children in their homes, all of whom live on Malaysia's mainland. Their families were immensely grateful for the education that their children were receiving for the first time. They spoke about the significant advances the children had made, even in the relatively short time that the school had been open.

As so often in isolated teaching settings, staff feel a constant need for further training and reinforcement of what they have already learnt. The Principal, Suresh Kumar Pandian, has asked if Dbl is aware of a trained teacher in deafblindness who might be prepared to provide intensive support on a volunteer basis at the Home for an extended period. If any member is interested, please contact the Dbl Secretariat in London.





SOUTH AFRICA

Andre van Deventer, who is deafblind, reflects on the history of deafblind work in South Africa in his article 'From Darkness and Silence to Light and Sound' which appeared in Deafblind News in April 1998.

Education for deafblind children in South Africa began in the early 1950's when the first deafblind pupil, David A Gever, was enrolled at the School for the Blind in Worcester, a town about 70 kilometres north of Cape Town. The deafblind department had only one staff member Miss Katie van Rensbury, who played an important role in the establishment and further expansion of the deafblind department for many years. Unfortunately, these services were only available to white people.

In the 1990's deafblind units were opened at the Sibarile School in the Guateng province and at the Arthur Blaxall School in Kwazulu-Natal. These units now accept pupils from all races, religions and culture. At present the unit at Pioneer school in Worcester, has nine pupils while the one in Siborile has seven. Two children are integrated into a class of the multi-handicapped at the Arthur Blaxall School.

A problem that still exists in South Africa, is that there are no programmes for deafblind children who have some hearing or sight and who, with some help, could attend programmes in either schools for the deaf or for the blind. Interestingly, institutions for the deaf form a very small part in the establishment of services for deafblind children.

Services for deafblind adults

Except for a few institutions and sheltered workshops which provide jobs, housing and some recreational services for the blind and the deaf, there are no existing services for deafblind adults in South Africa. Apart from services provided by family members and some staff members in institutions, there are also no intervenors. This is mainly due to the lack of specialist training for intervenors working with the deafblind.

As reported in the last edition of Dbl Review, Deafblind South Africa was formed in July 1997 to campaign for services for the deafblind. It aims to serve deafblind people of all races, cultures and creed, and in 1998 has finalised its constitution at their first deafblind general assembly.

The process of identifying deafblind people is another major obstacle. Due to the past history of South Africa, it is now a challenge to identify deafblind persons in disadvantaged communities. Compared to other developing countries, South Africa has a fairly strong infrastructure, but there is still very little money available for work among the deafblind. The challenge to conduct an intensive and extensive identification programme is huge.

Another problem is language. South Africa has eleven official languages and very often, due to the nature of dual sensory loss, deafblind people can only specialise in one language. This often creates communication problems between deafblind people themselves and also makes

it very difficult to hold meetings.

It is my firm belief that the only way to improve services for deafblind adults and children is for professionals working in the field to join forces with deafblind people themselves. The different ways of thinking which exists between professionals and disabled people, can often lead to nothing constructive being achieved. The two groups must not be allowed to grow far apart.



INDONESIA

Sr Agatha of the Institute of Dena-Upakara reports on a newcomer to the deafblind unit.

Since the last edition of *Dbf Review* we have been joined by Damayanti, a 46 year old deaf woman who is suffering from the eye condition Retinitis Pigmentosa.

Damayanti, known as Yanti for short, was born deaf and attended our education programme as a child. She left in 1969 at the age of 17 years with good oral language. In recent years Yanti has had problems with her vision and has been finding it increasingly difficult to lip read. Although Yanti is able to express herself verbally, she is unable to understand what people are saying to her. For this reason she has returned to the Institute to receive support through our deafblind unit.

Our work with Yanti has involved a short 2 month

programme called 'New way of Communication and Orientation Mobility'. This has been an intensive programme focusing on teaching Yanti a tactile version of Indonesian sign language. Fortunately, Yanti is a fast learner and now confidently communicates with others using hands-on signing. Our photograph shows Yanti speaking with Brigitta whom we talked about in the last *Dbf Review*.

When Yanti joined us she was lacking in self

confidence. Alongside developing Yanti's communication we have also focused on adjusting her daily living skills and mobility to take into account her visual problems. This has involved sports, including swimming, and basic Braille.

We have also been working with Yanti's family to ensure that when she returned home her family were able to communicate with her through sign language. Yanti will be returning to us in February 1999 for a second intensive programme.

Working with Yanti has been a great experience and has given us great satisfaction in being able to help her.

Since our last report we have also moved. Our new address is:

SLB/G-AB Helen Keller Indonesia, J1. Garuda, Gang Terati no:3, Murangan, Medari, Sleman, Yogyakarta, Indonesia.



RUSSIA

Usher Forum – Guardianship for Usher and Deafblind People

Irene Salomatina, Director of Usher Forum, writes about the recent formation of this organisation.

On 14 February 1998 Usher Forum was founded by a group of eight specialists, parents and deafblind people. It has been established to support deafblind people in Moscow and throughout Russia. We were officially registered by the Moscow State Registration Office on 3 June 1998.

Usher Forum is not a new

organisation but the restructured Socio-Pedagogic Association, known as Rainbow. Originally founded in 1980, Rainbow developed its activities as a non-registered public community. Usher Forum has inherited Rainbow's main principles: 1) an equal attitude towards people with deafblindness and other associated problems; 2) broadening public awareness of people with deafblindness through voluntary activities by different groups.

As adopted in our Constitution, our Mission is to support and realise programmes and projects devoted to the rehabilitation of deafblind children and adults, who have sight and

hearing loss through Usher Syndrome and other causes. We promote the legal rights and interests of deafblind people to achieve a good quality of life. We aim to achieve our mission through the creation of a network of services throughout Russia.

Despite our deep roots, we remain a young organisation and are open to support and advice.

For further information please contact:

**Irene Salomatina
Director, Usher Forum
Novoalexeevakaja str.
18-1-210, Moscow 129626,
Russia**

Telephone: +7 095 928-36-88 or email: irv@child.ru



CHILE

In August 1998 Mary Guest, Head of Usher Services, Sense (UK) made a return visit to Chile after 30 years. In Santiago, Mary met up with Irving and Laura Augustine who are helping CORPALIV, an organisation working with deafblind and multi-sensory impaired children, to establish services in Chile.

Irving and Laura are from Canada and work with the Navigators, a Christian based organisation who focus on start up projects. In Santiago they are working with a number of Chileans with CORPALIV to set up a school and teacher training with families of children with multi-sensory disabilities.

During my visit to the home of the Augustines I met two young deafblind adults, Jaime Bustos Palma and Paz Yáñez. Jaime is 18 and wants to go to college, and Paz is 24 and currently

studying education at college. We spent a morning together discussing their hopes and problems using a combination of English and Spanish finger spelling. Both Jaime and Paz want to meet other

young people, have fun, get an education and eventually work. They face the same problem that affects many deafblind people: that professionals working in vision and hearing fields do not collaborate to give an integrated service to deafblind people.

CORPALIV have just moved into a larger house which will give them scope for more activities. There are also plans to use the new space for young deafblind



Jaime Bustos Palma and Paz Yáñez enjoy lunch at Irving and Laura Augustine's house in Santiago.

people to meet up socially, get to know each other and plan a programme for themselves. Hopefully, this programme will reach out to other young deafblind people in Santiago which is now a city of 7 million people.

MEXICO

Yvette Gallegos de Soto writes on behalf of ASOMMA, the first association in Mexico created with the sole purpose of serving deafblind people and families including those with additional disabilities.

ASOMMA, the Mexican Association for Multiple Disabilities, began in 1993 with 3 children that were 6 months old and whose families were looking for a service that met their children's needs. At that time no service worked with this group and their families were depressed by the very negative prognosis for their children.

After 5 years of hard work, patience and more

importantly love, the group of children has grown to be 6 in number and ASOMMA is now working with the Special Education Department to promote good practice for deafblind children through joint working. In addition, another group of 5 deafblind toddlers has just started in an early intervention programme.

Although its still very early days, the work in Mexico exemplifies the benefits of collaborative working and ASOMMA thanks the



parents, the Special Education Services in Mexico City, Perkins School for the Blind and Sense International for helping a dream become a reality.



EAST AFRICA

Penny May Kamau is a Projects Co-ordinator in the East African region and editor of Deafblind News. She reports on projects in Uganda and Kenya, and the publication of a new booklet.

Uganda

The Uganda National Association for the Deafblind (UNADB) has continued to meet on a regular basis to co-ordinate the work in the country. The association has also been able to network with many other NGO's and in this way increase public awareness.



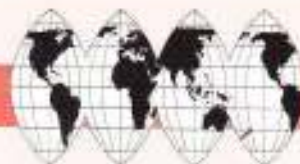
Alfred Ojok is pounding groundnuts to make a sauce to be eaten with the matoke

Sixteen year old Stephen Imalingat peels a matoke green banana



Buckley Deafblind Unit Buckley High School, a girls primary boarding school, carried out an awareness programme through the media, religious leaders, local councillors and MP's of the area. As a result of this awareness campaign, the management of the school was able to establish a small part of the school budget for the unit. The unit currently has five deafblind students, including Stephen Imalingat and Alfred Ojok who can be seen in our photographs.

The unit still faces financial problems as parents find it difficult to pay school fees. The school needs funds for fencing the compound around the unit, the salary for the housemother and a second dormitory. The school has already written a funding proposal to start a poultry project which, it is hoped, can help solve some of the financial problems.



Kenya

Kwale Deafblind Unit

In March 1998, in-service training courses were held at



Omari Bakari, 12 years of age, with his teacher

the Maseno and Kwale deafblind units. Teachers had the opportunity to gain more knowledge on assessment and implementation of individual programmes for

their deafblind pupils. The training was also an opportunity for facilitators to follow up on those teachers who had attended the regional workshop for teachers of the deafblind.

As with the situation in Uganda, the main problem facing the units is the lack of funds as most parents are not able to pay fees. The Kwale Deafblind Unit near Mombasa currently has 10 deafblind children and seven teachers. The unit cannot engage an extra house mother because the town council is unable to meet this cost. The school is also planning to start a poultry project as soon as sufficient funds are found, which, it is hoped, will in turn provide much needed protein for the children while at the same time giving some income to the school.

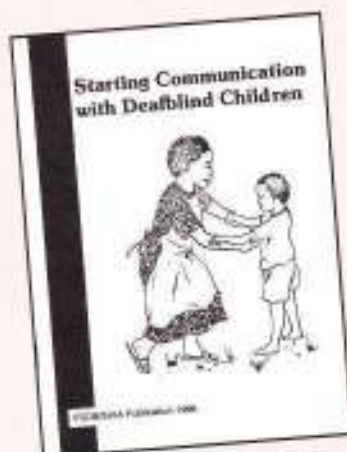


Nine year old Riziki Kassim

Starting Communication with Deafblind Children

This new booklet has been produced in the East African region by a group of 14 teachers of the deafblind under the guidance of Inger Rodbrøe and Eva Britt Andreassen, of The Swedish Deafblind Association.

This booklet is important as it represents the first specialist material which has been based on local experiences and culture. The booklet comprises chapters on: **Key Principles when you are with a deafblind child; Pre-linguistic Communication and Natural Expression; Total Communication and Making an Individual Plan;** and includes illustrations and diagrams.



For further information on the activities in East Africa, please contact Mrs Penny May Kamau, PO Box 63168, Nairobi, Kenya, telephone +2 48028, fax +2 48026, email: shiapmk@africaonline.co.ke.

CORRECTION

In the last edition of *Dbi Review*, it was reported in Regional News that Mr David Shaba of Tanzania had been selected as the African representative of the proposed World Federation of the Deafblind.

This was incorrect and should have read Mr Andre van Deventer from South Africa. We apologise for this error.



NUD

Anny Koppen, Director of NUD, reports on another busy and creative year for the Nordic Staff Training Centre for Deafblind Services (NUD)

In 1998, our courses and conferences have dealt with some complex and interesting topics. In particular, important discussions arising from the realisation that the population of persons with age related deafblindness is larger than first anticipated. We have also identified the benefits of using computers as technical aids; and have done much work on finding methods for accurate early diagnoses of congenital deafblindness, and on early interaction and prelingual development.

Our new contract with the Nordic Council of Ministers illustrates the need for international participation and co-operation. Even if most of our resources are still allocated to work in the Nordic countries, we are aware of the need to spend more on international projects.

NUD's mission is to provide staff training and development activities which support work with deafblind persons in the five Nordic countries. We also aim to promote Nordic co-operation between professionals in the field of deafblindness.

In both services for persons with congenital deafblindness and persons with acquired deafblindness, a tradition of co-operation across the national borders is well established. As a consequence, the whole of the Nordic region is seen as a natural arena for discussion on issues relating to deafblindness. In our experience it is beneficial to have the scope of opinions

that the five countries can provide.

Leading staff from the major services for congenitally deafblind persons meet yearly for the "Resource Centres' Meetings". At these meetings information is exchanged on developments and achievements within each of the five Nordic countries. Plans and projects are then co-ordinated when deemed beneficial, with a decision on bi-, tri-, or multilateral participation.

The major services for persons with acquired deafblindness also used to meet annually, but have decided to continue their exchange and co-ordination in a smaller forum; the "New Forum for Co-operation in the Field of Acquired Deafblindness in the Nordic".

Established in September 1997, this Forum was created with a representative from each of the five Nordic countries. The director of the NUD also attends these meetings. The Forum meets regularly to exchange information on activities, and to co-ordinate and initiate projects for development in the field. It has now met twice at the NUD, in February and September 1998. Its members are:

Kirsten Jansbol, Director, Information Center on Acquired Deafblindness, Denmark

Lauri Mikkonen, Head of Ävik, Home for the Deaf and Runola Home for the Deaf, Finland

Lilja Thorhallsdottir, consultant, Deafblind Association, Iceland

Elisabeth Olafsen, Head, National Central Team for Deafblind Persons, Norway

Trudi Wickström, Project co-ordinator, Mo Gärd Support and Information Service, Sweden.

A network of Working Groups has also been established. They report to and through the NUD and focus on the following topics:

- Communication of persons with acquired deafblindness (activity has started).
- The assessment of persons with acquired deafblindness (activity is planned).
- Exchange of information on computer based assisting devices (a mailing list is established).
- Age related deafblindness (activity has started).
- Model for introductory training on national and regional basis for staff in the services for persons with acquired deafblindness (working group in creation).

The Forum encourages and initiates development, discusses proposed project ideas. For example, a long-term study of communication methods in persons with Usher Syndrome in the Nordic countries, has been proposed and discussed.

The Forum also reports to the NUD on the training needs of staff who work in services for persons with acquired deafblindness.

The NUD supports the work of the Forum and Working Groups by offering travel subsidies, accommodation at the NUD, secretarial assistance and wherever necessary translation/interpretation.



NEW ZEALAND

The Nordic Staff Training Centre for Deafblind Services (NUD) continues its tradition of courses and conferences with its 1999 programme.

16 – 22 January	The Profile of Development Congenitally Deafblind People (Training course)
6 – 9 February	Deafblindness and Genetics (Conference)
1 – 19 March	Basic Training Course on Congenital Deafblindness, Part II (Part I held November 1998)
11 – 30 April	Basic Training Course on Acquired Deafblindness, Part II. (Part I held October 1998)
8 – 12 May	Adults with Congenital Rubella Syndrome (Conference)
8 – 12 September	Interpreting for Deafblind People (Training Course)
12 – 19 September	Open House Study Week*
26 September –15 October	Basic Training Course on Congenital Deafblindness, Part I (Part II to be held in 2000)
30 October –3 November	Language Development in Congenitally Deafblind Persons (Conference)
21 November	Rehabilitation of Persons with
–3 December	Acquired Deafblindness (Training Course)

In addition to these sessions a range of seminars and working group meetings will be arranged in order to focus on particular topics identified by forums of the five Nordic countries. The aim of these events is to strengthen the development work for the services for deafblind people.

* The annual "Open House Study Week" also offers working facilities and a meeting place for other types of working groups to meet.

December 1998 marks the tenth anniversary of Deafblind New Zealand's Incorporation and we are pleased to announce the launch of our website on the Internet, writes Patricia Clark, Webmaster and Vice-President Deafblind NZ Inc.

The site presently has three pages and is accessible to blind users. The Home Page is the first and includes Deafblind NZ's logo and motto 'Arm in arm we walk together. Hand on hand we talk together'. The second page gives a brief description of how Deafblind NZ came into existence and there are hypertext links to other, world-wide, deafblind Internet sites. Page 3 is a list of Deafblind NZ's achievements in its ten year history. The success and strength of developments means there is only room for a dozen of the most important milestones.

The website is still under construction so comments and suggestions for improvement are most welcome. There are also plans to add excerpts from our newsletter *SEE HEAR*. The website address is [http://](http://www.deafblind.org.nz)

www.deafblind.org.nz

Deafblind NZ Inc. is an organisation for people with dual disability of deafblindness/ vision and hearing impairments, and is operated almost entirely by deafblind/vhi persons themselves.

For further information please contact the national office of Deafblind NZ Inc., PO Box 109-583, Newmarket, Auckland, New Zealand; telephone +9 524-8598; or visit our website!

**AUSTRALIA**

The West Australian Deafblind Association (Inc.) are pleased to announce the next National Deafblind Conference to be held 7-10 April 2000 at the Esplanade in Fremantle near Perth.

Friday 7 April will be a pre-conference training day specifically aimed at professionals and support providers. A pre-requisite for this day will be that participants are currently or will be providing support to deafblind people. Saturday 8th and Monday 10th will be conference days with Sunday 9th as a social activities day.

In addition to the conference proceedings, a

cocktail party is planned for the Friday evening, a conference dinner on the Saturday and hopefully a barbeque on the Sunday!

The keynote speaker will be Graham Hicks from Sense in the UK. Graham is deafblind and is Sense's Specialist Advisor on Campaigns & Public Policy. Funding limitations has unfortunately restricted the number of invitations to international speakers. However, WADBA are willing to negotiate accommodation costs and waive registration fees, to encourage the involvement of international colleagues. The call for papers will be announced soon.

A survey has been circulated with WADBA's newsletter *Good Vibrations* to find out what participants would like on the Conference's agenda. Responses received thus far have included, not surprisingly, education, training, communication and challenging behaviour.

For further information and suggestions please contact:

WADBA

6th Avenue & Whatley Crescent

PO Box 14, Maylands WA, 6931, Australia

Telephone +8 9272 1122;

TTY +8 9370 3524; fax: +8

9271 3129 or email:

wadba@nw.com.au

CANADA**Late Manifestations of Congenital Rubella**

The Canadian study on congenital rubella is largely complete, writes Stan Munroe, Project Co-ordinator. One hundred individuals with, or with suspected, congenital rubella syndrome participated in this study which was funded by the Canadian government during 1997 and 1998.

Participants' ages ranged from five to sixty-two years of age and covered all ten Canadian provinces. Preliminary statistics, based on the first 75 respondents, were published in the 6th Canadian Conference Proceedings. The final report will be available by the end of the year from the National Office CDBRA, 350 Brant Avenue, Brantford, Ontario Canada N3T 3J9; tel: + 519-754-0729; fax: + 519-754-5400; or email: cdbra.nat@sympatico.ca

Check out CDBRA's new WEB SITE

The CDBRA is proud to announce its new Web Site which is intended to be an umbrella site for CDBRA, its Chapters, and other organisations and facilities which serve or advocate for individuals who are deafblind in Canada. If other international organisations want to link up with our Web Site please let us know.

Visit us at

<http://www.cdbra.ca>

Canadian Registry for Individuals who are Deafblind

The Canadian Federal Government Branch 'Human Resources Development Canada' recently advised the CDBRA that it had approved its application for a grant for a project entitled "Registry of Persons who are Deafblind in Canada". The grant covers

the period 1 October 1998 through to 31 March 2000. The purpose of this project is to develop a voluntary registry for all individuals across Canada who are deafblind. This will involve a major initiative to locate all individuals previously identified and those not previously identified with deafblindness.

The overall intent of this voluntary registry is to ensure that all individuals who are deafblind in Canada have access to proper services and programs, including education, housing, transportation and recreation through Intervention. The collection of vital demographic information on a select Canadian population will assist government and non-government agencies to plan for and implement appropriate services across Canada for this specific population.



The Sense Scotland 1998 Helen Keller Award



'Heads' by students at Sense West (UK)

The Helen Keller Award produced a stunning exhibition of works of art in a variety of media which has been on show at Glasgow College of Art since the beginning of November. The Princess Royal presented prizes to the winners at a prestigious civic occasion at Glasgow College of Art.

The overall winner was a work entitled 'Heads' by students at Sense West under the tutelage of Marie-Lise Chilcott. The work was commended for its strong tactile, reflective and visual qualities.



Deafblind artist Gry Segerblad from Norway receives her prize from The Princess Royal



A view of the exhibition at Glasgow College of Art

Canadian Conference on Deafblindness, 1998

Harmony abounded at the Delta Meadowvale Conference Centre in Mississauga, Ontario, August 12-15, 1998, the venue for the 6th Canadian Conference, sponsored by the Ontario Chapter of the Canadian Deafblind and Rubella Association.

Over 200 participants from across Canada, the United States and Europe enjoyed a four day event which harmonised uplifting plenary sessions, broad ranging and informative workshops, interesting poster sessions, good food, continuous fellowship, networking and fun within the ever present musical theme. Conference organisers were convinced that the conference theme **Let's Celebrate Our Harmony Together** successfully met its expectation.

The conference opened with professionals playing tribute to the families who



India's First National Meeting on Deafblindness, 1998

Akhil Paul, Development Manager for Sense International (India) writes about India's first national meeting on deafblindness.

In September 1998 more than fifty senior people from throughout India came together for India's first ever national meeting on deafblindness.

Organised by Sense International (India) the purpose of this meeting was to bring together representatives from NGOs, schools, government and other organisations to discuss the situation in the country and consider possibilities for increasing the number of deafblind services in the future.

The keynote address was given by Dr Anthony Best, Headteacher of RNIB Condover Hall School who focused on the specific needs of deafblind people and highlighted the essential components that programmes serving deafblind people should have. Further presentations



Sheela Sinha with Zamir Dhale and Pradip Sinha, two deafblind men from the Helen Keller Institute

were given by experts from Sense (UK), the Instituut voor Doven (Netherlands) and the Hilton/Perkins Program (USA). The participants discussed these issues in smaller workshops, considering the Indian context and putting together strategies for the future. The

reports from the workshops formed the basis of a concluding discussion from which five key resolutions were agreed:

- 1 Recognition of deafblindness**
Deafblindness should be recognised as a unique

have been integral partners in the education of deafblind children. Families then thanked and honoured the professionals who give so much in making life full and rewarding for the person in their family who is deafblind. This exciting evening included the unveiling of a commissioned art work 'Lend a Hand' by an accomplished artist Eddie LePage and inspirational humour and music from a talented performer, Terry Kelly, who is himself visually impaired.

Keynote addresses included Terry Kelly, once again with motivation, fun and music; Jeannette Lambermont, Stratford (Ontario) theatre director for 'The Miracle Worker'; and

Anne Malatchie alias 'The Cat', highlighting the new (1998) Dr. Seuss book 'Hooray for Diffendoofer Day'. The final plenary session included an international panel discussing Intervention around the World. The panel consisted of Jenny Fletcher (Sense, Birmingham, UK), Knut Johansen (Solveigs Hus, Andebu, Norway), Linda Alsop (SKI HI, Utah, USA) and Linda Mamer (CDBRA, Vancouver).

Organisers arranged for tours to attend 'The Miracle Worker', a visit to downtown Toronto, and a tour to the Niagara Falls along with a wine tour and the opportunity to play golf. Participants were provided with entertainment

to unwind, meet, mingle and connect – in a word harmonize – following the busy daily sessions. The conference closed with a Gala Dinner and Dance on Saturday night.

Proceedings from the conference are available for \$25.00. Copies of the 'Lend a Hand' print are also available for \$20.00.

**To purchase either of these items, please contact:
Ontario Chapter, CDBRA
350 Brant Avenue
Brantford
Ontario
Canada N3T 3J9**

**Tel: 519-759-0520
Fax 519-759-1425.**

and separate disability and this should be reflected in all relevant legislation and official policy documents.

2 Identification

The population of deafblind children and adults should be properly surveyed and all disability surveys should include deafblind people.

3 Training

Recognised training courses for staff who work with deafblind children and adults should be established and there needs to be an increase in professional development opportunities for those who work in the deafblind field.

4 Parents

Parents should have the right to be included in the planning and delivery of services and the creation of opportunities for families to meet and network should be encouraged.

5 Partnerships

The development of partnerships and the creation of networks for organisations and individuals working with deafblind children and adults should be encouraged.

The attendance of so many directors and senior figures from disability organisations throughout the country ensured that the meeting

was an extremely valuable occasion. There was a tremendous atmosphere and a genuine feeling that people want to work together to ensure real progress in service developments nationwide.

A detailed report of this meeting together with a list of participants, a summary of the programme and copies of all the presentations is available from Sense International.



Jessica Hills, Chairman of Sense, inaugurates India's first family seminar

ROMANIA

Ciprian Gimbutu is Romanian and works for Sense in the UK. He reports on the first National Seminar on Deafblindness in Romania.

In May 1998 more than fifty people from throughout Romania came together for the country's first ever National Seminar on Deafblindness. The participants came from a wide variety of backgrounds and included teachers, government officials, deafblind people themselves and representatives from organisations for deaf people and for blind people. The seminar was hosted by the University of Cluj-Napoca and organised by Sense International; presentations were given by a team of experienced staff from Sense.

The seminar was organised as a result of suggestions from a wide range of people in Romania who felt that it would be an appropriate way of addressing the need for more information about deafblindness. During the two days many issues of relevance to the field were covered, including: introduction to deafblindness; congenital deafblindness; acquired deafblindness; services for deafblind children; services for deafblind adults; partnerships; communication; and an international overview.

In addition to the seminar the team from Sense visited three schools for deaf children to give in-house training and advise on assessment techniques. Lectures were given to Special Education students at the University of Cluj-Napoca, a regional seminar was organised in the North-



▲ **Ciprian Gimbutu speaking at the first National Seminar on Deafblindness in Romania**

Eastern city of Iasi and meetings were held with the Government's Department of Special Education.

The main purpose of these events was to satisfy the need for more information and to bring together Romanian colleagues to consider future possibilities, to offer detailed training and support to various centres. Perhaps the most encouraging outcome has been the activities that have happened since the seminar. In June a group of parents of deafblind children came together and launched the new Romanian Parents Association and a further twelve organisations have proposed follow-up projects which are currently being discussed in more detail. The future is looking extremely promising and there are many people who are now convinced that it will not be long before substantial services for deafblind people start to emerge in Romania.

▼ **At the school for deaf children in Sibiu**



XIV Congress on Blindness , Argentina

Silvia de Altamirano, Vice-president of the Argentine Association of Parents of People with Deafblindness, writes about the successful ASAERCA Congress held in Bahja Blanca, Argentina between October 8-11th, 1998

A national meeting of parents was convened by the parents of children at the School for the Blind (507) when the XIV Congress on Blindness organised by the Argentine Professional Association for the Education and Rehabilitation of the Blind and Visually Impaired (ASAERCA) was held in the city of Bahja Blanca. The aim of the meeting was to establish the Association of Parents of Children with Visual Disabilities in the Argentine Republic.

Lots of interested parents,

68 in all, from faraway points of this vast country participated. They started the discussions with the hope of constituting a parents group that can fully represent all their children's needs and aspirations and improve their families' quality of life. Three days of hard work led to a final agreement to set up an Association and to draw up the general guidelines that will benefit disabled children and their families.

The Association will have a representative from each province of Argentina and as many delegates as



necessary. It will meet in the city of Bahja Blanca as a Provisional Commission until the next ASAERCA Congress which will take place in Buenos Aires in the year 2000. As a mark of its support for this development ASAERCA has decided to invite a parent to take part in their meetings

3rd Sense International Professional Development Programme

The 3rd Sense International Professional Development Programme (PDP) will take place between 27 September and 5 November 1998 and applications for participation are currently being accepted. The PDP continues to provide 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 has been recognised as a vital part in ensuring the sustainable growth of services for deafblind people throughout the world. Hundreds of professionals have benefited from the opportunity of participating in international staff development programmes and their services offer proof. Past participants have gone on to develop and improve their own services.

In the past, we have very much enjoyed the possibility of working with other INGOs and the PDP has proved to be an appropriate mechanism to do so. If you feel that any of your project partners might benefit from attending the PDP, we would be delighted to hear from them.

PLEASE NOTE THE DEADLINE FOR RECEIVING APPLICATIONS IS 31 MARCH 1998.

For further information please contact: Professional Development Programme, Sense International, 11-13 Clifton Terrace, Finsbury Park, London N4 3SR, United Kingdom; telephone: +44 171 272 7774 or 281 4373; fax: +44 171 272 6012 or email: si@sense.org.uk



1997 PDP participants (back) Dalia Tauriene from Lithuania, Daniel Holzinger from Austria, Don Waibe from Papua New Guinea; (front) Vimal Thawani and Meena Nikam from India, and Sr. Justina Obiajunwa from Nigeria

Valery Chulkov – A Reminiscence

Like others, I was saddened to read of the passing, at such a young age, of Valery Chulkov from Russia. While at first I noted that he passed away on my birthday, his smiling photo brought a memory back to me which I will always remember and which I wish to share.

It was a strange day for me, over four years ago, at the railway station in Warsaw, Poland. I was arriving from Canada en route to Bydgoszcz, location of the IAEDB



Executive Meeting and Symposium. I had spent the night on a train, first from Hanover to Berlin, then on the Polish Railway from Berlin to Warsaw. I was one of a handful of passengers and I was feeling quite alone in a very strange land. I arrived at the cavernous Warsaw Central Station where I believed I was to meet a group for a bus trip to Bydgoszcz. But there was no group; no bus; no English; only fear and loneliness in a strange city! The words on the signs meant

nothing. Remembering a memo, I waited in the Information Area for the scheduled time for the bus connection, but no one else was around.

"Did they get the message?", I wondered. "Was I at the right location?" "Was there a time difference I was not aware of?" I must have looked conspicuous, because just minutes before the scheduled time, a man approached me, and in broken English said "I'm Valery Chulkov, are you waiting for a bus (to a deafblind meeting)?" My heart started to beat again, and while I don't remember my exact words, they were along the lines of "Thanks for noticing me; I'm saved?" What relief, thanks to Valery. I stayed close to him and his interpreter for several minutes until a lady from the bus approached us. She knew Valery would be there but was unaware I was to be collected too.

So Valery saved the day back on April 12, 1994. Thank you Valery and thank you for your wonderful contribution to the lives of individuals who are deafblind in Moscow.

Stan Munroe, CDBRA

Dear Editor

I write to inform your readers of our service – Servizio di Consulenza Pedagogica.

Established in 1972 for Italian speaking people around the world, we work with families and parents of deaf, blind, deafblind, Down's Syndrome and Autistic children. We offer correspondence courses, Summer programmes and week end residentials on areas relating to these disabilities. Our Service is free for parents.

Our publications include a quarterly newsletter of parent's exchanges and letters called *Notizie* (News) and a yearly bibliography in Italian on hearing, sight and speech defects, *Bibliografia Italiana sui Disturbi Dell'Udito Della Vista e del Linguaggio* (1998:21st Volume).

dr C. Salvatore Lagati
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Pedagogica
Via Druso 7
P.O. Box 601
38100 Trento
Italy

Telephone/fax: +39 461 82-86-93

The World Federation of the Deafblind

The Helen Keller World Conference on Deafblindness held in Colombia in 1997, was an historical event for us deafblind people. During the last day the participants decided to establish The World Federation of the Deafblind (WFDB)

I think that an international deafblind organisation of our own will give us several advantages in our work to make our situation better. Deafblindness is a unique disability, with special problems that need special solutions. In WFDB we will get our own profile and it will be easier for us to reach out with

our message.

In Paipa in Colombia a committee was elected, given the task to start work and to prepare for the first general assembly. I was trusted with the chairmanship. The other committee members are: Roderick MacDonald, (Hawaii) Vice-Chairman, Jane Eriksen (Sweden) Treasurer, Yolanda de Rodriguez (Colombia), Irene McMinn (Australia), Andre van Deventer (South Africa), and Lex Grandia, editor of The International Newsletter for the Deafblind. The aim was to choose a committee with knowledge of international work and good contacts with all parts of the world.

The WFDB committee wishes to reach as many new member

countries as possible. Would all organisations that have not already contacted us, please do so as soon as possible! The address is found below.

Stig Ohlson
Chairman WFDB
c/o FSDB
S-122 88 Enskede
Sweden

Fax +46-8-659 50 42
E-mail: wfdb@frukt.org

The Secretariat of Deafblind International is currently updating DbI's membership records. A Contacts Questionnaire has been sent to all known members and associates of DbI to ensure appropriate and accurate information is held by the Secretariat. If your Questionnaire is not received by 1 March 1999 you will not be entitled to receive *DbI Review* and other relating information.

If you have not received the Questionnaire by 1 February 1999 or have any queries relating to Membership then please contact Tamar Underhill, Assistant Secretary, DbI, 11-13 Clifton Terrace, Finsbury Park, London N4 3SR or email: dbi@sense.org.uk.



Deafblind International, formerly known as the International Association for the Education of Deafblind People, was founded over 30 years ago to promote the education of deafblind children and young adults throughout the world.

The Association originally brought together professionals working with congenitally deafblind people. In recent years it has begun to work with adventitiously deafblind people. Professionals, researchers, families, deafblind people and administrators are now involved.

Membership

There are two categories of DbI membership: **voting** and **non-voting**

Voting members consist of corporate bodies and international networks. Corporate members are requested to subscribe an annual amount of between US\$300 and \$5,000. Corporates have the opportunity to sit on DbI's Council and vote at the General Assembly. **For further information and an application form for either Corporate or Network membership please contact the DbI Secretariat.**

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.

I wish to receive *DbI Review* in English Spanish

I would like to receive *DbI Review* on disc

I wish to become a **non-voting** member of DbI. Please find enclosed my donation of US\$30

debit my Access Visa American Express Mastercard

Expiry Date _____

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

Please return this to Deafblind International, c/o Sense, 11-13 Clifton Terrace, Finsbury Park, London N4 3SR, UK.

Title (Mr Mrs Dr etc.) _____ Surname _____

First name _____

Organisation _____

Address _____

Town/City _____ County/State _____

Post/Zip code _____ Country _____

Tel _____ Fax _____

Email _____

Signature _____

