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Review



Families in Nepal

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

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

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

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

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

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

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Cover: Nepali families

A message from the president

There has been a tremendous amount of activity since the New Year! We had a very successful and well-supported Council meeting in The Netherlands in February and a change in format was widely welcomed. It provided greater opportunity for discussion and a greatly enhanced role in decision making for Council members. The hard work redesigning our constitution has been done and will take us forward with more clarity as we develop. The Secretariat, now based in India, is continuing its good work supporting all our activities: an initial, major task has been to overhaul the membership lists and encourage more members to join us.

There are plenty of opportunities coming up for us to meet and share. There is an Acquired Deafblindness Network Conference in England in October, a DbI / ICEVI Conference in Nepal in November and, as I write this, we are preparing for our parents event in Denmark! Next summer we are planning another DbI European Conference. Slovakia, a beautiful country, is our host and we look forward to welcoming a record-breaking numbers of participants from all over Europe and the world. Everyone is working hard to ensure that all these events are accessible to everyone.

We are continuing to collaborate with international partners like the World Federation for the Deafblind and ICEVI – this is very much in line with our aims and



objectives and provides a major benefit to all of us. Our campaigning Networking Group based upon EDbN scored a major success this spring – and you can read in the magazine – but it has shown us all that pressure, applied in the right way, brings results and that working together gives us a stronger voice. You will also be pleased to know that, in recent weeks, our application for United Nations recognition has been sent off.

As we are fundamentally a networking organisation it's great to report some exciting successes. I have recently been involved in the Culture 2000 project, an amazing cross-national development in arts and theatre for deafblind people who love the arts – and those who are just beginning! Another first has come from South America, where a virtual conference, organised by Council members, was held, and deemed to be a great success.

Thank you for all your hard work wherever you are in the world – your support is vital.
William Green

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EDITORIAL

Thank you to all the contributors to this edition of the Review. I think you'll agree that, as we look again at a cross section of our work, skills and knowledge are being developed in many different cultural contexts by a hard working membership.

This round up of our work includes very significant research findings from Denmark about the effects of congenital deafblindness as people get older. This is an area of work that has implications for almost every long-term service providing organisation and every person who is affected by CRS and other conditions. We also have the guidance for practitioners on communication strategies that resulted from Isabel Amaral's research, reported in the last edition.

As usual we get a snapshot of activity from all round the world and what is striking is that so many of the initiatives being reported are collaborative – involving more than one Dbl member or institution working together. Our Networks are designed for this purpose but increasingly this way of working is becoming second nature to us all. Our cover story involves families in Nepal and celebrates their invitation to Lone Poggioni, herself a parent from Denmark, to visit and share experiences. The outcomes of this adventure speak for themselves. Joint working features in work in Latin America, which focuses on young people and the kind of intervention they require to join in with others, and also in the formation of a new support group in Russia!



Romania too has seen some tremendous developments in recent years, thanks to the vision and commitment of the government to encourage professionals with the development of a training course. We hear about this success and the personal views of a young professional in the field. And in India too an exciting development for children in the very early years has started and we look forward to hearing more about its outcomes for children in the future

Again, thanks to my regular contributors who keep us up to date with their country and Network news.

All good wishes and please stay in touch ...
Eileen

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The ageing process and the late manifestation of conditions related to the cause of congenitally deafblind adults in Denmark



The Information Centre on Congenital Deafblindness

The Information Centre on Congenital Deafblindness in Denmark conducted a survey that began collecting information in 1999. In this article, Birthe Laustrup, Director of the Information Centre, summarises the main findings of this research. The complete report is available in Danish.

The purpose of the survey

This survey has collected information about the ageing process and late manifestations of the causes of congenital deafblindness.

Who participated?

Everyone, aged 18 and over, diagnosed with congenital deafblindness in Denmark is included in the survey – 58 individuals in total. 53 of the participants stated that the aetiology of their condition was known. The 5 without a diagnosis were all within the non-rubella group. Two thirds of the group live in residential settings for congenitally deafblind people, and the other third live with a person or people with other impairments.

What did it do?

The survey compared 26 individuals, diagnosed with congenital rubella syndrome (CRS), with 32 individuals with other aetiologies.

Terminology

The statistical data is organised as a “rubella group” and a “non-rubella group”.

When the term “both groups” is used, variables applicable to both the “rubella group” and the “non-rubella” groups are referred to.

The Summary Findings

Medical and physiological information

The rubella group has more males than the non-rubella group.

Weight

In both groups there is a high incidence of persons born “small for date” (born at term, but with lower birth weight than expected). In both groups there are many individuals who later in life have experienced weight problems. In the non-rubella group, there is typically a problem of undesired weight loss. This contrasts to the rubella group where it is more common to become overweight in the adult years. According to the data collected the problems of weight gain is of a scale that calls for further investigation to identify the causes of this.

Heart

Congenital heart failure primarily occurs in the rubella group. With early surgery, the heart defects pose no problems for the individuals later in life.

Motor development

If we look at the motor functions and physical impairments present at birth, these only occur in the non-rubella group. However, in both groups there are individuals who later in life experience physiological deterioration to such an extent that they need assistive

devices for mobility functions. In the non-rubella group this deterioration takes place early in life, and in the rubella group only takes place from age 30 and onwards. This may indicate the presence of a late manifestation of their condition.

In both groups there is a relatively high incidence (15,5%) of muscular deterioration and poor balance in adulthood. This reinforces the requirement that congenitally deafblind persons need treatment from physiotherapists and occupational therapists during adulthood.

Vision and hearing

The majority of the participants, in both groups, have a visual impairment that was diagnosed during the first year of life.

Around two thirds of the population with congenital deafblindness have a progressive vision loss (like glaucoma, retinal detachment, decreasing visual field, and removal of an eye). We can also attribute the generally occurring age related changes in vision to much the same level in both groups. The Danish survey indicates that:

persons with CRS are at high risk of developing late manifestations e.g. glaucoma;

the combination of glaucoma and cataract is specific to the diagnosis of congenital rubella syndrome;

retinal detachment is also significantly more frequent in the rubella group. A possible trigger factor might be cataract;

Microphthalmus is present in every second individual in the rubella group and in every fourth in the non-rubella group;

there may be a relationship between microphthalmus and later development of glaucoma.

In both groups individuals have severe hearing losses or deafness (the latter is more frequent). "Moderate" hearing losses are only identified in the non-rubella group. Both groups show that the hearing impairments are identified later than the visual impairments.

Individuals in the non-rubella group are generally diagnosed earlier than individuals in the rubella group. This finding may surprise, as a congenital cataract, possibly in combination with low birth weight and heart failure should cause suspicion of a concurrent hearing loss caused by a rubella virus infection.

Hearing aids

According to our information 50 individuals had a hearing aid at the time they were diagnosed. Today only 16 individuals still wear their hearing aids. Progressive hearing losses are identified in both

groups. However, the prevalence of progressive hearing losses may be higher than shown in the data collected, as, unlike progressions in vision loss, the progression in hearing loss will not be immediately detected in observations of changes in behaviour. For this very reason it seems alarming that appropriate examinations are not being undertaken at regular intervals.

With regard to hearing and vision losses the survey records that the awareness of the risk of progressive sensory impairments is lacking in the environments where congenitally deafblind adults live. The survey also indicates that there is more awareness of the possibilities of decrease in vision. This is because every second individual is regularly taken for eye examinations, and only one in five gets their hearing checked.

Hormonal conditions

Problems with metabolism are a known late manifestation of Down syndrome, and have been mentioned in foreign studies as a late manifestation of congenital rubella syndrome as well. None of the participants in the Danish survey reported any diagnoses with regard to metabolic problems, so it may seem not to be a matter of late manifestation.

Nevertheless, we must state from the data collected that 10 out of the 20 individuals in the rubella group are overweight and in the same 10 people between 2 and 6 symptoms of low metabolism (e.g. tiredness, sadness, increase in emotional instability, passivity, less stamina and weight gain) are reported.

Foreign studies demonstrate that CRS entails a major risk of developing diabetes. In our survey we identified a few cases of diabetes (3), in the rubella group only. Whether this finding is a statistical coincidence or it actually expresses a late manifestation cannot be judged from the present study.

Growth retardation has been mentioned as a specific problem in persons born with CRS. We have identified cases of growth retardation in both groups, but the prevalence is clearly higher in the rubella group.

Neuropsychological conditions

Epilepsy, according to our information, occurs with almost identical frequency in both groups, but the age of diagnosis is different.

In the non-rubella group the epilepsy is diagnosed at an early age and must be considered a part of the clinical picture. The reports of individuals having epilepsy in the rubella group confirm the assumption that epilepsy is a late manifestation – likely to appear in the teenage years.

In our survey we also asked for information on changes in neuropsychological phenomena like attention, concentration and memory. Here we find

distinct differences in the two groups, as decreased ability in these three functions is remarkably more frequent in the rubella group. Our survey, which comprises all aetiologies present in our country among people with congenital deafblindness, shows that reductions in memory and attention are late manifestations significant to the diagnosis of CRS. A number of individuals in the non-rubella group also report increasing problems with concentration, thus the difference between the two groups is less significant.

Development of behaviour problems

In our survey we asked for information on changes in behaviour in 11 different areas. They are: self stimulation, motor agitation, self abusive behaviour, aggression, tolerance to changes in routine, levels of confusion, restlessness, increased impulsivity, initiative, ability to start an activity, difficulties in changing from one activity to another.

In six of the areas there is a dominant score from individuals with CRS.

Self-stimulating behaviour, motor agitation and increased self-abusive behaviour are three types of behaviour which primarily are identified in the rubella group. This tendency seems to confirm the hypotheses of a late manifestation with respect to an increase in these types of behaviour. There is a significant difference between the two groups.

Increased aggression, less tolerance to changes in routines and increased levels of confusion are three types of behaviour which have previously been considered as late manifestations of CRS. These behaviours are relatively frequent in both groups, however, with the difference that aggression and less tolerance to changes in routines are much more significant in the rubella group, which could indicate a connection with the original diagnosis.

There is also the possible explanation that these three types of behaviour express general deprivation in the congenitally deafblind individuals, or are related to early ageing processes. We know from gerontology that the behaviours mentioned may also be observed in the normal ageing process.

Increased restlessness and increased impulsivity are described as late manifestations of CRS in previous foreign studies. Our study cannot confirm this. According to our data increased restlessness and increased impulsivity is reported in both groups, but not extensively.

These behaviours are also known from gerontology studies.

Less initiative, a fall in ability to start activity, as well as more difficulties in changing from one

activity to another are also behaviours which previous studies have characterised as late manifestations of CRS. However, none of these types of behaviour seem to be characteristic of any of the two groups in our study. Despite a small minority of the rubella group showing these behaviours our data cannot confirm previous assumptions. As these behaviours are also described in gerontology, they may be indicators of early ageing processes.

Among people who work with congenitally deafblind people it has often been discussed whether these types of problem behaviour could be explained by environmental factors.

We have therefore tried to identify possible common features of each person and their environment when the focused behaviours occur. None of them seems to depend on whether the setting is deafblind specific or not. Nor can we state a correlation with the individual's general level of functioning or ability to communicate.

Psychological state and psycho-socially conditioned factors

In total the study investigated 11 types of behaviour: emotional withdrawal, increased separation anxiety at social withdrawal, frequent waves of sobs and increased passivity, less energy, depression, emotional instability, lowered frustration threshold, sleeping disorders, sleeps only a little and circadian problems

Two of these are reported as low frequency for both groups. Five of the remaining nine are recorded with moderate frequency in the behaviours scored, with much the same level in the two groups. Four variables have scores in both groups, but are clearly higher for the rubella group.

Emotional withdrawal and increased separation anxiety are, according to the findings in our study, not a particular problem among congenitally deafblind adults.

Social withdrawal, more frequent waves of sobs and increased passivity, are behaviours that are seen in one in five congenitally deafblind persons, with nearly the same occurrence in both groups. As these behaviours also are known in gerontology, they may be tokens of early ageing.

Less energy seems to be a problem to every third congenitally deafblind person in both groups. We cannot find a clear explanation to this. Could it be the lifelong deprivation caused by the deafblindness? Is this a sign of early ageing? Could the explanation be something so simple as too little exercise?

The risk of developing a psychiatric disease is relatively high in both groups. The only difference between the groups, which can be stated, is that the

disease is diagnosed at an earlier age in the non-rubella group.

Depression is the most frequent diagnoses in both groups. Is this caused by a permanent state of deprivation or is it due to early ageing?

Emotional instability occurs more frequently in the rubella group than in the non-rubella group. The survey reports it in every second individual with CRS and one in four of the deafblind persons with other aetiologies.

The same is reflected in the findings related to a lowered frustration threshold; again the problem is present in every second individual with CRS and in one in four in the non-rubella group. Is this evidence of late manifestation in the rubella group? Or equally is it a symptom of early ageing?

Sleeping disorders, sleeps only a little and circadian problems reveal a significant difference between the two groups. Every second individual in the rubella group experiences considerable sleeping disorders, whilst in the non-rubella group we speak of one in six. The absence of residual vision affects the individuals in the rubella group most. In this group the data indicates a significant correlation between early infection during gestation and severe sleeping disorders later in life.

The individuals among whom we have rated all these problem behaviours constitute a representative section of the congenitally rubella group of the deafblind adult population in Denmark that lives in sheltered homes.

Viewed from the level of functioning, the group studied is also highly representative, apart from those individuals who manifested sleeping disorders. They are basically persons who, to a certain extent, are able to communicate in a linguistic way with their environments.

Concluding comments

The changes in behaviour observed in the rubella group that are significantly different from the non-rubella group might indicate rubella-specific late manifestation of the syndrome. Changes of neurological or physiological character take place in some of the organs of these individuals, which result in the onset of problems at somatic, behavioural and psychosocial levels in adulthood. Some indications may point to earlier ageing in the rubella group than in other people.

When facing changes in behaviour we must question whether internal factors, external factors, or a combination of both, are the trigger of the changes observed. At first it must be clarified whether the cause could be an unknown somatic condition, a

neurological condition or decrease in hearing and/or vision. Attention must be paid to the sudden or gradual character of the changes observed. A neurological and psychological assessment is also important, and the individuals' interaction with their environments must be observed and analysed as a part of the total evaluation of the person's situation.

We recommend annual health checks for all persons with congenital rubella syndrome. In Appendix 2 of the full report there is a guiding checklist, which may be presented to the physician examining the person with CRS. Also, we again stress the importance of regular appointments for examinations of hearing and vision. In general, there is a need for far more attention to be paid to the risk of deterioration in the two main distance senses for the deafblind population as a whole.

If we look at how quickly changes take place in the two groups studied with respect to the variables scored, it appears that within the two-year period of our survey the positives occur almost exclusively in the rubella group (reported in Appendix 3 of the full report). If this is a valid tendency we can estimate that within five years the differences between the two groups compared will be even more important.

Future work

The Information Centre on Congenital Deafblindness recommends that this survey should be followed up by a quantitative study of the same group of individuals starting no later than 2006. Until then, qualitatively oriented interviews may contribute to the development of the existing knowledge in identifying useful details from selected participants. Experience-based development is still needed in this very important area and there is evidence to suggest that there is a clear advantage when this work is combined with medical research. Systematic information of this kind would be highly valuable to the clinical work in our field and considerably contribute to an increased quality of life for the individual with congenital deafblindness.

Translated by Elin Ostli

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HOLIDAY INVITATION FROM SWEDEN

Dear Friends,

This year our friends in Sweden are arranging the European holiday week – from Monday 5 July until Sunday 11 July.

Accommodation will be at Mullsjö folkhögskola (a folk high school), well known for its large number of international courses and training programmes. The Association of the Swedish Deafblind has for many years arranged many courses there for deafblind people. The school is very well adapted for persons who are visually impaired or wheel chair users and all rooms are equipped with a bathroom. The school is located in a picturesque setting, overlooking a lake with the same name, Mullsjö. A beautiful 23km walking path runs along the lake and there is a nice place to swim, not far from the school. For someone who loves nature, Mullsjö is the perfect holiday resort – calm and peaceful with a lot of untouched natural surroundings. The school is situated at 15 minutes' walking distance from the centre of Mullsjö, where you can find several shops, restaurants and other facilities.

The nearest airport is Axamo in Jönköping and the school is a 20 minute drive away. Flights to Axamo leave from, among other places, Arlanda (Stockholm) or Kastrup (Copenhagen). If you have access to the Internet and want some more information, please go to www.lfv.se, click on "Airports" and then "Jönköping" and you will find some useful information to get prepared for your holidays and you can also find a map of the surroundings of Mullsjö.

During the holidays we will offer many recreational, cultural and social activities including excursions, tandem bicycling, handicraft, sports, games, horse riding – just to mention a few. But more than anything, we believe that spending time together is important, and we will allow sufficient time for that. In addition, it is naturally up to each and everyone to either take part in all the activities or to do something on your own – it is a holiday after all!

We hope to see you all in Sweden! Welcome!

Kind regards, Mia Nyström

(On behalf of Mona-Britt Broberg, chairman)

Costs

The total cost of the holiday amounts to EURO 340 including accommodation, full board and activities.

If you wish accommodation in a single room the cost is – EURO 430.

NB: Travel to and from Mullsjö is not included!

Language

In order for everyone to be able to communicate during the holidays we'll be using English. Therefore it is important that the deafblind participants (or their interpreters/guides) speak English.

Insurance

The participants themselves must make sure that they have appropriate insurance for the journey and for the stay in Sweden.

Application

If you are interested in taking part in the holiday for deafblind people in Sweden, please fill in the attached application form and return it directly to us or via your organization!

A detailed programme will be sent to you later on.

If you know any deafblind people who might be interested in this holiday, please forward this message to them or send us their address. If you want to get more information or if you have any questions, please don't hesitate to contact us:

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Another world in Russian Petersburg! Another success for deafblind people!

A charity called "Opened World" has been recently founded in St. Petersburg. The real life circumstances of deafblind children and adults moved those involved to realize the need to found a charity. Experience of Sense UK also helped.

How did it begin?

First we got acquainted with two families. In one family there was a deafblind boy who had not only hearing and sight impairments, but mobility problems as well. The other family has a deafblind girl who had heart problems in combination to her hearing and vision impairments. Though her problems are quite complicated she is very active. These families stimulated us to start thinking about how we could help them. In our native land there was practically no information about how to work with children with such complex difficulties. We became involved in a Russian-British partnership project "Giving Voice to Deafblind People in Russia", which gave us an opportunity to learn about the UK experience in person. During our visit to the UK we were able to appraise the scale of support to deafblind children, adults and families. We found out that deafblind people are free to unite into different associations and that this was not considered as anything unusual but as a natural aspiration of different groups in defending their rights. We understood that we could use the experience we gained in order to continue our work.

Gradually other people

started to join us. Students from the Pedagogical University named after A. Herzen and Raul Valenberg University became our volunteers. They learned more about deafblindness, helped us at our seminars, read correspondence, guided and interpreted, etc.

Contacts with The Centre for Non-Profit Organisations was also very useful. We attended their training courses on the foundation of a charity and how to get official registration. Their help was just right for us when we took our first steps.

Simultaneously we kept looking for allies in mass media circles. In this respect I would like to stress our partnership with Radio "Maria". Over a two year period, eight programmes were devoted to the problems of deafblindness and three of those to our Russian-British partnership

project. We hope that our cooperation with Radio "Maria" will get stronger.

So we can see that our work has developed in several directions. The main aim was to deepen public awareness about deafblind people and prepare soil for the foundation of a charity.

On March, 18th, 2004 the charity "Opened World" was officially registered in the Department of Justice.

We hope that, together with other Russian and foreign organizations, we will solve the complex and very difficult problem of deafblind people in our city.

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Members of "Opened World"



Kathmandu and the people of Nepal – what an experience!

Lone Poggioni made her first visit to this fantastic country during March this year. She was invited to meet families. Armed with her personal experiences, as the mother of a deafblind son, and some construction bricks for the children, she has created a momentum which will be taken forward by the Nepali families.

The girl had very weak eyesight and could not talk at all, but she was very excited with the DUPLO bricks and started immediately to play.

After a very long flight from Copenhagen I arrived for my first visit to Kathmandu! It was very exciting because of what would happen to me over the next days. My stay in Kathmandu was to be seven days long, and during this time I was overcome by a great deal of strong emotion.

The day after my arrival, during an information meeting with our contacts, I was informed about the programme for my stay in Kathmandu. I had to visit some families of congenitally deaf blind people, as well as a school with four blind children and finally attend a 2-day workshop.

Visiting the families

On my third day I started my visit to the families. A very nice taxi driver, an exceptionally kind man, Mr. Madhav Aryal, who was my translator, and I, with a distinguished and ancient car, took the trip to the first family. With me I had some DUPLO construction bricks for the deafblind children and I felt very apprehensive to visit and talk with their parents.

We left Kathmandu through the city's dirty and dusty streets and drove for about one hour, uphill for two kilometres through small country lanes, dusty and full of potholes. Finally, when our car could not drive up the hill any more we had to walk the

last 2/3 km. The trip almost totally exhausted me; so steep and slippery was the road! Finally we reached the family which was composed of a grandmother, father, mother, an older sister and two congenitally deafblind brothers 8 and 11 years old respectively. It is impossible to describe the poverty I saw and my feelings at the sight of the two very nice, but underfed and apathetic deafblind brothers sitting on the floor. Most of the time they were left to themselves with their sister, since their parents and grandmother had to work in the fields. Without their work they would not even earn the modest pay of \$50/65 a month to live on.

I gave the brothers the DUPLO bricks and, after a cautious start, they slowly found out that the bricks could produce sound and some of them could even move which was exciting to feel with their hands. We say hello to each other "namaste" and try to play!

Our next visit was to a family with a 17 year old congenitally deafblind son. Mr. Madhav Aryal told me that the first contact they had had with the family was two years ago, when by chance they found the son lying in a loft without any stimulation and with very little contact from people. As I saw him my heart was crying with pain.



He was a small boy of 17 with frightened eyes, who for the family was only a shame, and therefore hidden from the world – not seen nor heard.

The last visit was to a family with three deafblind grown-up children. The youngest was 19, the sister 25 and the eldest brother 27 years old.

Denmark is second only to Japan in being the country giving the highest economic support to Nepal, but I can only confirm that there is a strong need for more help. The three brothers had received free hearing aids from the company Oticon in Denmark, but since they had no more batteries, and could not afford to buy any more, it was a great loss for them. This was felt especially keenly by the youngest boy, who had acquired good language thanks to the hearing aid.

Getting help from the public administration in Nepal, for instance for batteries or hearing aids for disabled persons, not to mention special teaching, is unthinkable, due to the lack



Animals and people live in simple habitations

The Grandmother and her grandchild examine these "strange" bricks.



of financial resources. But what a nice family!

It was difficult to fall asleep after having witnessed such poverty and seeing what a miserable life deafblind people lead. But although the first visit had given me a lot to think about, I discovered that there are families that live in even worse conditions.

The next day we visited a very nice 11 year old deaf blind girl. Her home was so unimaginably poor. Her only contact during the whole day was with her old grandmother, since the parents had to work in the fields to earn just few Nepali Rupees.

The girl had very weak eyesight and could not talk at all, but she was very excited with the DUPLO bricks and started immediately to play.

The last visit was to a family with a 7 year old girl, who was perhaps the "most fortunate" of the congenitally deafblind people I visited, because her parents understood her condition better and had a normal income.

Because of the distances and very bad roads

unfortunately we could not manage to visit more families.

Workshop for parents

Due to a general strike our workshop was postponed by two days, but finally when the workshop did happen it was a great pleasure to see how many parents had travelled long distances to Kathmandu to participate. The first day they had their deafblind child with them and the day after they came alone. It was the first time that they had taken part in any such meeting and had the chance to talk with other parents sharing the same problems, frustrations, sadness, anger and hopelessness.

The workshop was introduced by Nepal's government politicians, with encouraging words, but, I fear, empty promises. The official opening of the workshop was broadcast on the local TV and there were even local journalists. All that public attention was



education and the family support programme.

It was pointed out that we were very happy to help them to get a project accepted by Danida in Denmark, but on the condition that the parents in Nepal took the initiative and that they (and not the government) were our direct contact. This way of thinking was completely new for the parents and had to be discussed with an internal debate.

Parents' organization

Just shortly before I left Nepal, I was contacted by the Kathmandu co-ordinator Renu who wanted to give me wonderful information. The

very positive, which is the first step to improve the living conditions of deafblind people.

I told of my experience as the mother of a young deafblind man and his life in Denmark and I explained what a traumatic change it is for a family to have a deafblind child. Then I showed video film with, for instance, different ways of

communicating and different teaching methods for the deafblind in Denmark. At the beginning the parents were very silent but listened with attention. After a few hours they started to ask questions and an interesting debate took place. A wonderful experience! The parents had great expectations from the Danish "know-how", especially concerning



parents had now established an independent parents' organization with the name "Society of Deafblind Parents", which was to be registered by Nepal's government and would take around 6 months to achieve.

I left the country with many thought provoking "pictures" printed in my mind, but also with my luggage full of hope. This was due to so many volunteers offering their smiles and help and wonderful parents ready to make the difference. I am sure that with the help of all the involved participants in this cause, this will be the start of a better life for the deafblind in Nepal.

Lone Poggioni
Danish Parents Association



The Intervenor

– a communication bridge between a congenital deafblind person and the world

Natalia Molina Llano has been a volunteer with Sense International (Latin America) since last year. She is studying Speech Therapy at Rosario University in Bogota, Colombia. As a volunteer she works with a congenital deafblind person and currently co-ordinates a pilot project called "Intervenors in the Day Centre for Young Deafblind Adults" The centre is run by the Colombian Deafblind Association.

In this article I want to share with you how, thanks to Pedro's existence, the Intervenors project for congenital deafblind people in Colombia started and how it keeps us thinking about the future for those who haven't reached a symbolic communication level.

Pedro, the centre of my story, is a 22 year-old young man with a visual impairment caused for congenital cataracts, hearing impairment and learning disabilities.

Since Pedro was a boy his parents, full of love for him, have visited several institutions, knocked on many doors, and Pedro, little by little has been learning and developing skills. However, others, making his social adaptation harder, have not understood his communication with the world.

Some months ago, after a certain time of being part of the volunteer group, I started wondering what could be crossing Pedro's mind in every moment of a day. His behaviour in the

Centre meant everybody kept away from him. He was isolated, rocking in a chair and removing little pieces of skin from his face. Since then I started to focus all my attention on this young man. I felt Pedro should be able to do the things that others do and that, with my help, as a communication bridge, Pedro might face the others

and the world. I set about developing a structured project that could help to meet this aim, restoring his self-esteem through the provision of support.

But I found out that the concept had already been developed! Through professional contacts, I found information that in Canada, Europe and specifically in the



UK, there are “Intervenor” programmes, which in spite of sounding strange was exactly what I hoped to become. I intended to intervene between Pedro and his world: Pedro and his family and Pedro and his desire to be part of a group of young people where everyone is building a better life with the help of all of us.

What is an intervenor?

An intervenor is the person in charge of opening the world to the deafblind person, providing him/her with significant information which he/she couldn't otherwise reach, and giving opportunities to take advantage of social and learning experiences which allow complete access to the environment and the school curriculum. In order to make all this happen, we can say that an intervenor's main functions are:

- to create easier access to environmental information;
- to facilitate the development of, and/or use of, expressive and receptive communicative abilities; and
- to develop and maintain an interactive and confident relationship which promotes social and emotional welfare.

In order to fulfil these tasks appropriately the intervenor requires special training about deafblindness, communication, mobility and all other aspects related to his/her work as an intervenor.

We – intervenors – have to interpret the meaning of information coming from the world so that people like Pedro can understand and use it for future learning. We intervenors need certain specific skills, such as knowledge about communication development,

experience of working with disabled people, being a good communicator, having good social skills, the ability to work in a team, a lot of initiative, a positive attitude, enthusiasm, patience, willingness and flexibility.

Step by step, as we have accomplished each stage with Pedro, he and I have built a mutual bond of confidence. When he sees me I feel that he recognizes me and that he knows who I am and I feel that I've reached his affection towards me and to other people.

His behaviours, previously called repetitive or stereotyped, have become for both of us communicative behaviours, now that I understand his desires and displeasures more easily, and we can do activities with a specific goal for his communicative needs. We have both developed skills for exploring and participating in group activities. It's very important to keep in mind that Pedro is the one who has to do things – not me! I've given him some challenges where he's surprised me and he has taught me to trust his capacities and to go beyond our own goals.

Until now we've experienced many things together, like using the Colombian public transportation service. We have learned how to get in and step off as if it were a game and with the expectation that Pedro would step off at the indicated station and not wherever he wanted to! I've visited his house and I know his family. We've gone to the park where he enjoys going down the slide with me.

Pedro laughed for the first time in the Centre when he was congratulated for a job well done! Now he doesn't

stop laughing when I tickle him. He has discovered the things life can bring him – things as simple as a lollypop. Pedro imitates our movements, gestures, and behaviours, he follows simple commands, he is beginning to socialise with other people, and he follows a routine and uses objects of reference to anticipate his daily activities. He likes music, which we've used as a means of communication. Little by little his initiative has been awakened. He often does more of the activities that he likes the most, but not the ones we tell him to do. He demands his own privacy, picking his snack while buying it, choosing the colours while painting his new reference box, creating an unusual style among painters but with plenty of real meaning attached.

Pedro's improvement has allowed us to learn new and meaningful life experiences, together, in God's world.

Intervenor are part of a pilot project; we want to help more young people like Pedro. We want them to have the opportunity of knowing the world through the intervenor when they are children. In the future we'd like to show off the achievements of the Intervenor Project in Colombia ... and why not in Latin America?

We intervenors are not exactly interpreters, because the communication system is quite individual; we're not teachers either because we're not teaching in a classroom directly; we're not guides because that's not our only role. We intervenors are those who listen with each part of our body, of course with our ears, but also with our eyes and our hands but especially with our heart.

We – intervenors – have to interpret the meaning of information coming from the world so that people like Pedro can understand and use it for future learning.

Synchronise the singing and dancing: thoughts on developing listening with deafblind/multi-sensory-impaired children



Patricia Gibbons is an experienced teacher of multi-sensory-impaired children and works in an advisory role in the UK, in the city of Manchester. This article is based on a workshop that Patricia first delivered at the conference of the British Association of Teachers of the Deaf.

Vision, touch and the other senses have a vital role to play in supporting the process of learning to listen. From 20 weeks gestation the foetus is aware of the mother's voice and the auditory components of the mother's body rhythm, as well as sounds coming from the outside environment. Pre-natal conditioning enables vibrotactile and kinaesthetic experiences to be associated with auditory ones. This, in turn, ensures that the baby will continue to develop an awareness of cause and effect after birth. Sounds made in the course of the usual care-giving will become linked with the tactual and kinaesthetic experiences and also with visual experiences as vision develops.

Satisfaction of the bodily needs is the early catalyst for developing sensory awareness. We are likely to see the first evidence of anticipation around care-giving behaviours such as feeding and cuddling. The baby alerts to the sensory clues – mother's voice and footsteps, sight of mother – in advance of being fed,

for example. As bodily control develops, and along with it the experience and understanding of causality, there is strong motivation for attempting to create the conditions for the sounds or visual experiences to occur – for instance kicking to make the mobile move and jingle. The whole process becomes very quickly intertwined – the baby might see an object or a movement, and link it with a sound, or feel it, or hear the sound and search for the cause, tactually or visually. This integration of sensory experiences supports the process of learning to be an active listener and to be in control of the body.

The child who has deafblindness or multi-sensory impairment will experience sensory stimuli and life in general, in a fragmentary way, making experiences difficult to decipher. Months or years of random, incomplete and isolated sensory stimuli lead to confusion and an inability to interpret or make use of sounds. This may very well teach a child to actively ignore auditory stimuli, which may be experienced as

disembodied noises. Failure to access visual information promotes the sensible response of avoiding or resisting touch, as well as reluctance to move around or reach beyond the body space.

Behavioural testing techniques for hearing are referenced against typical, integrated sensory development and depend on removing extraneous sensory clues to concentrate on a purely auditory response. For the deafblind/MSI child

Andy





Nico

this paring down renders the experience even more piecemeal, and possibly frightening. Such a child will probably emerge from a clinic assessment with inconclusive results. The child may only respond at “interest” levels, well above the threshold for hearing. Pure tones and warbles, less meaningful than complex sounds, and very fleeting, may be ignored. Often children with severe visual impairment may register a sound once, but then not respond again. In fact this one response may not be a fluke. It could mean, “I know it is there, but I can’t do anything about it so there is no point in reacting again.”

Teaching is more effective than testing if we wish to understand the child’s hearing, and it should be planned to promote sensory awareness and sensory integration. Cognitive development depends on exploration and learning to operate on the environment, and the objects in it. Alongside this, the child needs the support of an interactive partner, who is an

The first priority is to structure the environment – clear the decks of distractions and ensure that the child is in the best situation to respond.

able communicator. We also know that the pragmatics, or perception of purpose in the activity, is supportive of learning. The conditions for promoting learning are the same for children with complex needs, even if the end-game is different (for instance, we may only ever hope to achieve some non-verbal communication or relaxation to music).

Learning to listen takes place in a context of interacting, experimenting, getting feedback and experiencing success and satisfaction. Functional assessment of hearing and the development of listening is about building up a record, over time, of responses carefully observed within an ecological context provided by real activities: presenting meaningful sensory stimuli, synchronising sound with touch, or vision or movement, each stimulus feeding the other, so the child can organise an active response.

So, where should we begin? The first priority is to structure the environment – clear the decks of distractions and ensure that the child is in the best situation to respond. Make sure the child is comfortable, well positioned, not struggling to maintain balance, not distracted by a more demanding sensory experience. Use a tactual clue, such as a personal symbol or an action greeting, to let the child know who you are. Play to the child’s strengths. A child with extremely limited vision needs a social, tactile or vibrotactile feedback.

A child who can’t see, and is limited physically, is necessarily a passive listener, unable to search actively for sound or interpret it. We have to teach, with co-

active support, to locate and reach, rather than look, for sound makers. If the child is resistant to touch it will take longer to understand what is being offered but most will be willing to touch and may even reach if the experience is familiar, enjoyable and coherent. What we mustn’t do is give up, thinking the child doesn’t like it. Repetition makes the activity familiar, and once familiar it becomes first tolerable, and, later, even interesting.

Often hearing aids are pulled out, but it is unsafe to decide this is dislike – it could simply be evidence of noticing that there is something there (through touch or sound), it could mean “I’ve nothing better to do”, or that the background noise is thoroughly confusing. Sometimes it is helpful to target the use of amplification: putting aids on for an individual session, and taking them off at the finish (the very act of putting on and taking off becomes part of the communication, meaning “we’re going to work now” or “we’ve finished”).

Plan listening activities linked to body movements, moving together in harmony, aromatherapy massage, exploration of musical and multi-sensory toys, conversation around the activity the child is involved in. Lovely interaction, turn-taking, imitating (bodily movements and sounds), voice with intonation, play babble and singing all offer the chance for sensory integration. Even physiotherapy can be made tolerable if done in conjunction with music and massage!

Consider a range of approaches to amplification, and enhancing awareness of sound or its effects. A personal stereo could be used, if the hearing is good

enough, or an Auditory Training Unit to listen to music. Try a resonance board, with musical toys placed on it to get additional amplification and an aurhythmic sound box. Both help children to associate the vibration with the music.

Routines and sequences help the child to know what to expect, and learn to associate soundmakers with objects, actions or events. This will enable you to observe evidence of "cottoning on" to the sounds – the child may reach for the item associated, begin the relevant rocking motion, and show signs of anticipation.

Careful observation, and discussions with carers and classroom staff should help build up a picture of the way sound is being used, ranging from showing awareness (reflex responses), attention (stilling to listen), localisation (though this may not be possible if hearing is unequal, or associated with physical disability,

and the blind or severely visually impaired child may not turn), discrimination (recognising familiar sounds), recognition (knowing names or key words or sounds), and finally, comprehension (using sound as a cue and inferring meaning).

Record what behaviour indicates listening, liking or disliking. How does the child react if startled by sound? Compare responses with and without an auditory component – does sound make a difference? The child may stay engaged in an activity longer if music or other synchronised sounds are involved. The child may struggle to track a moving object visually, but perhaps there will be a difference in response if the object also makes a sound.

What else makes a difference to responses – closeness, loudness levels, complexity, human voice, musical, animal sounds, familiar school or domestic sound? What is the impact

of the environment – does it make a difference if you are working in a quieter room, an unfamiliar room, when it is cooler, before dinner? What responses are reported by mum, within a familiar routine?

If you are a visiting teacher, set up a regular sequenced individual session that can be repeated daily by classroom staff (or the family). Observe the child's behaviour at the beginning, and compare this with responses at the end of every few weeks. Record changes in demeanour – signs of interest, enjoyment, greater alertness, better looking, or increased tolerance of touch. Measure the sounds you feel confident have gained a response, and record the distance and position as well as the loudness level. You may not get results across an audiogram, but you will share some good listening.

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The Dbl Secretariat is supporting the information work of Dbl and in particular is beginning to develop the website. Parag Namdeo, with his colleague Shivkumar Sharma, have begun to overhaul the pages and make the information more up to date to reflect what the membership is up to across the world.

We are planning to redesign the whole site, when money allows. The format has never been revised and is out of date for our needs. In the mean time we will be making sure that current information is kept up to date so its easier to see new material at a glance. We are aiming

to respond to enquiries as quickly as possible – either by up loading items that you have sent for inclusion or responding when problems of access arise.

We were pleased to be able respond to requests to the support the European Campaign by placing information and contacts on the site and then encouraging the last push to get the support required to achieve their aim of recognition of deafblindness as a unique disability.

We will be thinking hard about how we take things forward and our intention will not be to replicate or imitate the organisational

websites of Dbl members, but to highlight them. What we will be doing is focussing on our Dbl identity and providing a responsive site for both members and those seeking information about us – or about deafblindness. To do this we will be providing clear links so that access, to the information that already exists, is easier.

For this new team it is still very early days. We will write again for the next edition of Dbl Review, but do get in touch if you have comments or suggestions, or if you have something you would like to have posted!
Eileen, Sumitra, Parag and Shiv





An Early Intervention Centre for children with multi-sensory impairments

In this article Mrs Meena Ramesh Nikam describes a new project which is developing work with early years children in Mumbai.

When Rohit, a toddler of four years old, went to play-school, his parents realised that he was different from other children. They noticed that Rohit had a problem with his vision and hearing and that he was lagging behind in gross motor skills and communication. He was four years old but was neither speaking nor mixing with other children. Changes in the environment would upset him. Whenever they tried to find out what was wrong with Rohit the answer came in very technical language. Many professionals tried to comfort them by saying that he would be okay as he grows older. However, his parents were worried and kept taking him to different doctors but no one would diagnose his problem in these early years.

This is not the story of just Rohit. There are many ... Sunita is five years old; she was a premature baby with visual impairment and speech problems; Ganesh is three years old and is deaf-blind; Anu is six years old, is blind and exhibits some autistic features.

The Need for an Early Intervention Centre

Though most of the children mentioned above do not have any physical problems, they are still not walking on their own, they prefer to play with their own body, and they are dependent on others for their daily living skills. As these children are growing older their parents are getting more concerned about their education and do not know where to go. There are many children like Sunita, Anu and Ganesh. These are the children with multi-sensory impairments.

Most of these children have a sensory deficit in vision or hearing, but there are also children who often have other complicating problems such as cerebral

palsy, mental retardation, behavioral and learning problems and developmental delay.

In India there is no survey regarding this population but it is estimated that there might be 350,000 children with multi-sensory impairments. At present, fewer than 200 are getting some kind of service, which is only 1% of the estimated population. That means that the remaining children have no facilities for their education and rehabilitation. Working with these children is very challenging because of the high cost of the programmes, the high teacher to child ratio, the need for individualised plans and the lack of trained professionals in this particular field.

Multi-sensory impairments

The early years of any child are an intensive learning phase. At this stage a child gains the variety of experiences, ideas and knowledge that becomes the foundation for his overall development.

affect a child's interaction with others, his acquisition of concept, language and motor development. This further limits his ability to learn from the environment and depresses his developmental process in relation to his peers. The development of these children is dependent on a range of factors, including aetiology, age onset of impairment and age of diagnosis, family relations, and whether a program of education or treatment was started at an early stage.

The early years of any child are an intensive learning phase. At this stage a child gains the variety of experiences, ideas and knowledge that becomes the foundation for his overall development. A child's early learning provides the foundation for later learning. Therefore, the sooner a special program of intervention is begun the further the child is likely to go in learning skills that are more complex. For most of us this process occurs in a very natural way but this is not same for children with sensory impairments.

The developmental effects of sensory impairments are dramatic and require considerable resources in order to help each child develop to full potential.

The Initiation of an Early Intervention Centre

After the successful establishment of a home-based programme for children with multi-sensory impairment in the city of Mumbai (and then throughout the country), the National Association

for the Blind, Department of Education decided to develop an Early Intervention Centre at the Mata Lachmi Nursery for the Blind at the Mata Lachmi Hospital in Mumbai, which opened in October 2003.

The main objective of this service is:

- To reach out to the maximum number of children at the earliest stage;

- To assess the children clinically and functionally;

- To help the families to accept their child through counselling;

- To work closely with the family members as a team and help them to understand the impact of disabilities on the child's overall development;

- To help parents to learn essential skills to deal with their child regardless of their financial or educational background

- To educate the child in his home environment so that he is able to use his skills without having the problem of skills transfer

- To provide support for the child and family that will prevent the child from developing additional problems or disabilities eg. assistive devices, hearing aids, low vision aids, mobility aids etc.

- To help families find additional support services such as referrals for appropriate educational facilities, medical assistance, financial aid, counselling etc.;

- To make maximum use of local resources (this helps in creating awareness

If the needs of these children are recognized at early stage and intervention by all necessary professionals is well coordinated, the learning and development of these children can be greatly enhanced.

about the existence of these children, their special needs and their potential).

If the needs of these children are recognized at early stage and intervention by all necessary professionals is well coordinated, the learning and development of these children can be greatly enhanced. Considering the fact that there is large number of children who need our services this project is just a beginning. However, we are confident that very soon we would be able to replicate such centres throughout the country.

Such Early Intervention Centres will lead to dramatic decreases in the degree of disabilities that result from being born with multi-sensory impairments and will enhance the development of the children.

Meena Nikam

The author acknowledges Dr. Sundribai Mirchandani, founder member of Mata Lachmi Nursery for the blind, for providing her with the premises and thanks the medical faculty in the hospital for their support.

Guidelines for Communication Intervention

In the last edition of the Review, Isabel Amaral discussed her research and this time we are following up with the guidelines that were developed to encourage communication.



in the development of communication plans for learners with multiple disabilities.

Learners' interactions with real life experiences should therefore be increased through conversations between learners and their communicative partners. Such conversations create opportunities for learning about environments and also for learning about what to ask, what to request, what to question or what to refuse in those environments.

How do we encourage turn-taking interactions and develop conversations with learners with multiple disabilities? How do we learn to base our interventions in real life experiences that support the development of communication about everyday life in an everyday setting? Finally, how do we encourage staff to understand and develop strategies to increase communication and learning opportunities?

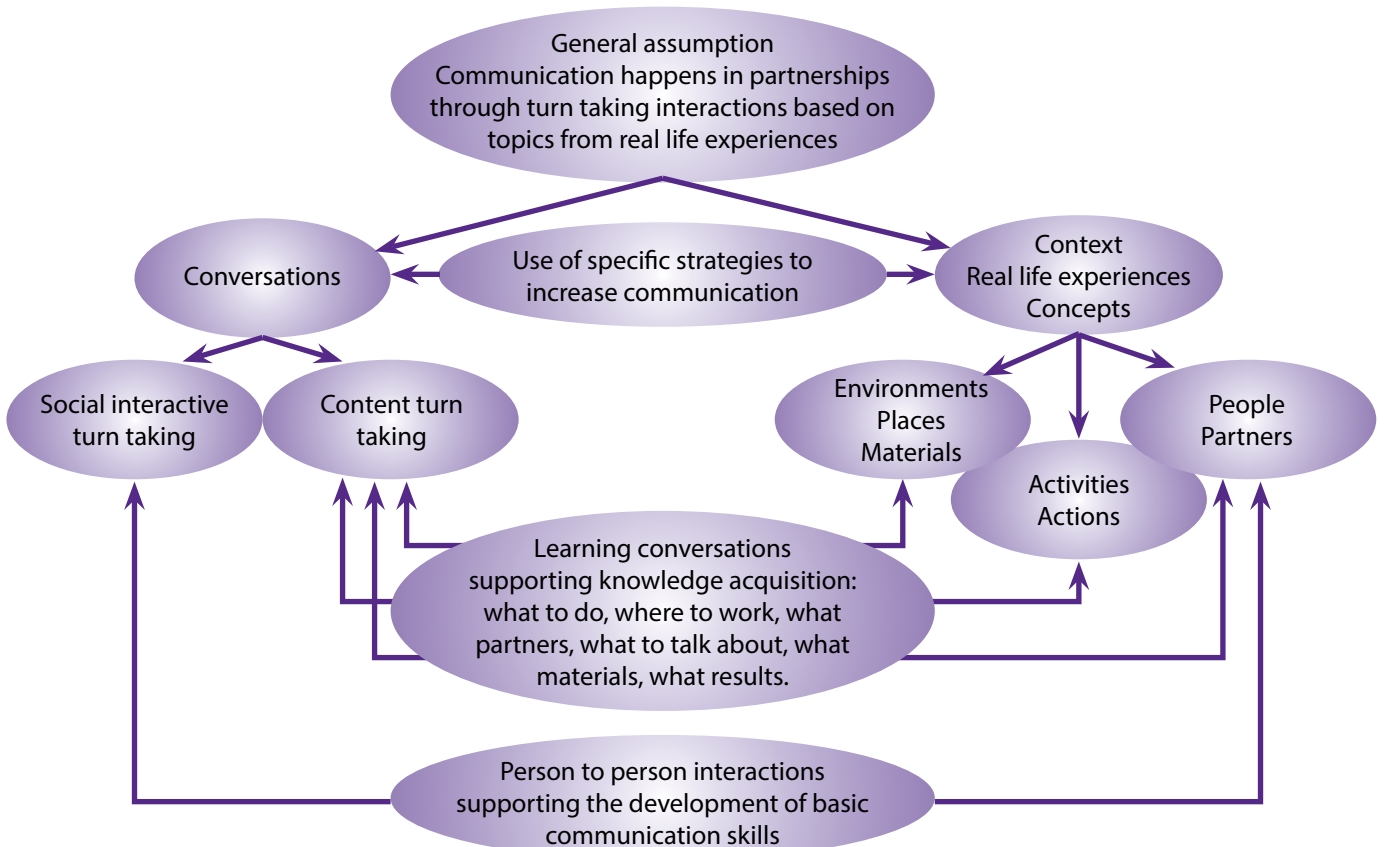
This model describes the way communication and learning interact, and how concepts such as turn-taking and real life experiences should be put together

How do we develop these conversations?

By developing social interaction

These kinds of activities enable teachers and children to trust and enjoy each other. Such interactions are usually based in movement, rhythm and repetition, and reflect the way mothers and infants behave when playing and talking together (Trevarthen, 1977). By taking a child's movement, repeating it and waiting for the child to show that he wants the movement to continue, both parties are engaged. The teacher can also initiate a movement the child likes, wait for the child to give a sign and then

Communication and Learning



produce the movement again. Van Dijk (1986) refers to these interactions as resonance, meaning that the teacher mostly provides resonance for children's behaviors.

By developing turn-taking

Social interactive turn-taking can lead to conversations on topics centered around an object, a person or an event. It requires the teacher and child to coordinate attention skills that enable them to jointly attend to objects, and to shift attention between the information provided by those objects, and information provided by partners in conversation (Mundy and Willoughby, 1998). It is the teacher's role to seize the objects, persons or events which most interest the child and use those as topics for conversations. Through this kind of conversation more topics can be introduced and longer turns can be encouraged.

By working in real life situations

The use of real life experiences in educational intervention with learners with multiple disabilities is based on several assumptions:

- That they mean something to the individual child in the context of his/her life, family and community and therefore provide a familiar context for activities;
- That they provide meaning that is easily grasped by children as it relates to their own needs;
- That they are part of the learner's normal life, and have a potential for repetition that supports learning;
- That they have clear outcomes which support the learner's understanding of means-end processes;
- That they happen in normal environments in order to provide for context and meaning.

By increasing communication opportunities

Communication is both a means and an end in the learning process of a learner with multiple disabilities. Learners need to develop communication skills but also need to use communication in order to learn about new subjects.

A set of topics should be considered in the development of communication opportunities for learners with multiple disabilities:

- Identifying, interpreting and responding to learners' behaviors; Learners with multiple disabilities often communicate through the use of non-conventional forms such as movements, eye gaze or objects. Teachers need to learn to identify behaviours as potential communicative acts (Sigafoos et al, 2000) and select the ones that better support the development of interactions.
- Encouraging initiation; Learners with multiple disabilities need to be kept active in the communicative process. Encouraging initiation supports the development of choice-making and prevents learned helplessness (Seligman, 1975) that is often a characteristic of learners with multiple disabilities.
- Developing the use of appropriate communicative forms; This can be achieved by selecting the forms

to serve the individual learner, and introducing more than one form whenever possible to enlarge communicative opportunities. Using selected forms consistently when communicating with the learner, and providing for new communicative forms whenever learners show that they can be given more abstract levels of communication.

By supporting the development of communication functions

Particular emphasis should be given to requests, negations and calls for attention, which are basic functions related to early communication levels. Modeling of different functions in context, creating communicative opportunities for the use of different functions, and providing learners with appropriate communication forms to express communicative functions are effective ways to develop and diversify the use of communicative functions.

By increasing the number of turns in interactions Interactions that rely on one turn are frequent in communication processes with learners with multiple disabilities who do not speak. Although social interaction is an important basis for the development of further interactive skills, content turn-taking needs to be explored and extended in order to support the introduction and exploration of meaningful topics from real life activities. Teachers need to encourage interactions to grow longer, by responding and expanding on learners' turns, and by including meaningful topics that provide content and support further learning.

By pacing interactions according to learners' needs Learners with multiple disabilities often have information-processing characteristics that require teachers to wait for answers longer than normal conversations would lead them to expect. Unless teachers learn to pace their turns with learners' turns, interactions will be non-synchronic, leading to frustration on the teacher's side and to withdrawal on the learner's side. In the long term, such asynchrony will result in a decrease of interest in interaction. Developing expectations about the learner's ability to take turns in a conversation, and providing time for the learner to respond, are two basic issues that teachers need to incorporate into their practice as effective communicative partners.

Finally

Teachers should organize activities in sequentially predictable ways, to help learners understand how an activity is developed and what the learner is expected to do in an activity. The use of routines in real life activities also supports repetition as activities are often performed in learners' lives. This will ultimately encourage awareness of the teacher's expectations, encourage initiation and support feelings of success.

References for this article can be found in Dbl Review 32

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NETWORK NEWS

CHARGE Network

David Brown reports:

2003 was an important and exciting year for anyone with an interest in CHARGE Syndrome. It is extraordinary to think that in less than seven months we saw the first ever European CHARGE meeting in Hinckley in March, the 6th International CHARGE Conference in Cleveland in July, the 13th Deafblind International World Conference in Toronto in August (with a meeting of the Dbl CHARGE Network, and also ten CHARGE presentations, compared to none at all at the last conference four years ago), and the US National Deaf-Blind Project Directors' Meeting in Washington DC in October (with a keynote presentation and a workshop both about CHARGE).

At the request of parents and other family members there has been a prime focus on behaviour at all these meetings. In Cleveland this resulted in a whole day of presentations about various aspects of CHARGE behaviour (with speakers from Holland, France, Norway, the UK, Australia, and the USA) that created a growing excitement and feeling of momentum as the sessions progressed. Several of these presenters also attended and spoke at the Toronto Conference. The topic is so complex that there was a wide focus and range of viewpoints presented; this confused some people in the audience who sensed contradictions where they were seeking clear-cut answers, but really it showed how much we are only just starting to explore all these ideas, and how far we need to go if we are to achieve a synthesis of them that will be truly helpful to each person with CHARGE.

The most practical outcome of the Cleveland meeting was that the American Journal of Medical Genetics has been asked to

consider publishing the texts of all these presentations in a single issue devoted to CHARGE sometime in 2004.

We hope there will also be an additional article written by three parents about behavioural aspects of their own children with CHARGE. The AJMG CHARGE issue should be a valuable resource to use in educating people about CHARGE, and should also provide a spur to further research

At the Deafblind International CHARGE Network meeting in Toronto it was agreed that I would act as secretary to the Network, maintaining email contact with anyone interested to try to ensure representation of CHARGE on the programmes of future Dbl World and European Conferences. The Network also set up a new listserv (kindly created by Lisa Weir) and anyone interested in knowing more about the Network and its listserv can contact me at dmbrown1@pacbell.net. The scientific programme committee for the 2005 European Conference (to be held in Slovakia) has invited David Levey (LEVEY2000@aol.com) to help in creating a CHARGE event at the meeting, and David is eager to hear from anyone who has ideas about this or who can attend and would like to contribute. Although I cannot attend the Slovakia Conference I am looking forward to participating in the French CHARGE Conference in September, and in the next Australasian CHARGE Conference to be held in Sydney in October.

If you are a parent what will all of this mean for you and your child with CHARGE? Probably not very much in the short term, even if you



were able to attend any of these recent meetings. There is so much that we do not know or understand about these children and young people that, in spite of all the intensity of activity in 2003, there is

a real feeling that we are only just beginning to ask the right questions and to share what we are thinking. But, for a very low-incidence condition, CHARGE is achieving surprising prominence in the field of

special needs, and future meetings will maintain this momentum of research and sharing.
David Brown
Education Specialist
California Deaf-Blind Services

Acquired Deafblind Network

Ges Roulstone reports:

The main piece of news from the Acquired Deafblind Network is the change of date and venue of the 2004 International Seminar on Acquired DB.

For reasons beyond the control of this year's host organisation, Sense, the dates of the conference have needed to be changed to Friday 29 October to Tuesday 2 November. This has been caused by a change to the venue. The conference will now be held at the Moat House Hotel in Harrogate in Yorkshire, not far from the ancient city of York itself.

However a happy consequence of these changes is a reduction in the cost! Attendance

at the conference, including all accommodation and meals over 5 days, is £655. This makes the conference cheaper than the World Conference in Toronto in August 2003. The complete seminar programme and registration form will be available in May 2004. If you would like to receive the



programme and registration form please contact Tracey Cook, PA to Divisional Director, Sense, 72 Church Street, Market Deeping, Peterborough, Cambs PE6 7LX. Email: tracey.cook@sense.org.uk Tel: 01778 382230.

In the meantime the co-ordinating group of ADBN met in Copenhagen in March. The group concentrated on finalising the programme of the 2004 seminar and considered a number of proposals for workshops which will make for an interesting and stimulating gathering between 29 October and 2 November.

The Siblings Network

Sabine Kersten

Since the last edition of Dbl Review a few things have happened. First of all The Siblings Network has been officially recognised by Dbl which will enable us to raise more awareness for the role siblings play within families, as well as for the Network.

The first siblings meeting took place in the Netherlands. On the 25th March the Siblings Network and Viataal organised a small meeting for siblings of adult residents living at Viataal. The main topic for the evening was "Responsibility, and who will take

care of my sibling when my parents cannot take care anymore". Only a small group turned up, but the meeting was very positive. We exchanged experiences and talked about the responsibility most of us feel. At the end of the meeting, everybody had a positive feeling and we agreed to plan another evening in the Autumn.

Finally, we are planning a Siblings Day during the Dbl European Conference in Slovakia in 2005. This day will be open for all (adult) siblings of deafblind children and adults. At this event

we will exchange experiences and have discussions on different topics. I would like to take this opportunity

to ask all organisations for and of deafblind people to fund a place for one sibling to come to this day.

For more information, I can be contacted by email: siblingsnetwork@gmx.net



The Communication Network

Marlene Daelman, Anne Nafstad, Inger Rodbroe, Jacques Souriau, and Ton Visser report:

In the last Paris Seminar arranged by the Communication Network the focus was on “the formation of meaning”.

This topic is still the focus of the Communication Network and has brought us to new scientific areas. These new areas might support us in our search to understand and describe the complex and unique communication we observe in many meetings between deafblind persons and their seeing-hearing partners. At the moment we are inspired by the collaboration with Sarah Taub, who is a professor of cognitive linguistics at Gallaudet University in the United States and by Professor Per Aage Brandt from the Centre of Cognitive Semiotics in Aarhus, Denmark.

Three new members have joined the group: Marlene Janssen, who has worked as a consultant and researcher at Viataal in the Netherlands for many years; Corinne Blouin, who is a consultant at Cresam in France; and Flemming Ask Larsen, who

recently finished his Masters degree in cognitive semiotics. His final thesis was based on semiotic analyses of some of the videos made by the Communication Network and this thesis has been a great inspiration to the work of the group.

Flemming currently works at Skådalen Centre in Norway as a consultant involved in a project with Anne Nafstad. In this one year project they are trying to apply the contribution of the cognitive semiotics to the practical educational setting, following the networks around 3 deafblind children at the school unit at Skådalen Centre. The goal of the project is to develop well-grounded theoretical approaches to describe and interpret the communication of deafblind children and to try out these approaches in clinical practice. This project is being followed closely at the meetings of the communication network.

The Communication network

has, during the last 2 years, had 3 meetings – all focused on understanding and trying to apply this new theoretical framework to the deafblind field.

Within the last year, two of the members of the network have finished their PhD. Marleen Janssen with the thesis: “Harmonious Interactions between Deafblind Children and their Educators”, and Marleen Daelman with the thesis: “An Analysis of the Presymbolic Communication of Blind Children with Multiple Handicaps – Prompting Pedagogy”.

The Nordic Staff Training Centre (www.nud.dk) website holds the Communication Update Series (CNUS texts) on the recent work of the Communication Network.

At the European Conference in Slovakia, August 2005 the Communication network will be in charge of the “communication stream”, which means that some of the work being carried out at the moment will be presented in Slovakia.

EdbN

Ursula Heinemann reports:



The recent major success of the Network is reported in full, as an article, elsewhere in this magazine. Words can barely describe how we felt when we heard the news that deafblindness has been recognised! But now we have this victory we have to build on it and, to that end, we will be putting together a strategy that will help us to make the declaration work in each country. This is quite a task and we have such a good team spirit going now I feel sure we will do it!

We also have to begin to think about the new countries, which have joined the EU on 1st May 2004. We will have to develop mechanisms for communicating with them and understanding their needs.

Finally, but very importantly, we will need to consider how EdbN will work and be funded in the future, so we can continue to move forward!

Please get in touch if you would like to know more about the Network or to join.

ursiheinemann@usa.net

Usher Study Group

Mary Guest

The Usher Study Group has now gone global. From our tiny beginnings in 1985 in Holland at St Michielsgestel Institute for the Deaf, with just a handful of people from western Europe we are now attracting participants from Africa, South America, eastern Europe and beyond.

It is not possible for everyone to attend in person each time we hold an Usher Study Group, but it is possible to keep up the connections and information flow to a wider group of interested people between meetings and between continents if we want to.

At the end of the Toronto meeting in 2003 we started the process of getting contact details from everyone who wanted to join the Usher Study Group Network and on our return home we sent everyone on the list information about the latest medical research.

Our next step is to invite others around the world to join the Usher Study Group Network if they:

- are ready to share practice and news in their areas.
- want to develop work on Usher.
- are keen to be active in the field of Usher work.

If you would like to know more and how you can join the Usher Study



Group Network (there is no cost), please contact Mary Guest and Melanie Gonsalves at Sense.

mary.guest@sense.org.uk
melanie.gonsalves@sense.org.uk
Sense 11-13 Clifton Terrace,
Finsbury Park
London N4 3SR
Tel: 00 44 (0)207 272 7774
Fax: 00 44 (0) 207 272 3862

Dbl Network Development Group

At the last meeting of Dbl Council in the Netherlands, in February 2004, it was recognised again that Dbl Networks are very important in the life of Dbl. At the same time, there was concern that some Networks that had been productive had disappeared, perhaps through lack of support or a feeling that they were not connected to Dbl.

To strengthen the link between the Networks and Dbl Council, it was decided to set up a small working party, to be given the task of making contact with all the Networks and opening up the communication channels between Networks and Dbl.

The members of the Dbl Network Development Group are Anny Koppen (Norway), member of DBI Management Committee, Sergei Sorokin (Sweden) and Mary Guest (UK). Each of us will take

responsibility for making contact with three to four Networks. Anny, who chairs our group, will report back to Dbl Council and Management Committee.

Our first task is to find out how the Networks are progressing, their plans, any difficulties and what relationship the Networks want with the rest of Dbl. A letter and survey questionnaire is being sent to each Network to be completed by August 1st 2004. The working party will analyze the results and a report will be presented at the Dbl Management Committee at their meeting in November in Nepal by Anny Koppen.

The during the summer Anny, Sergei and Mary will take responsibility for making contact each with 'our' group of Networks to find out how they are progressing. As a result of this contact we hope that the valuable

work which the Networks carry out in Dbl will be strengthened and progressed.

Watch this space for more Network News in the December issue of Dbl Review!

Mary Guest June 2004

Working with deafblind children in Romania



Andrea Hathazi, is a special education teacher, who is working for her PhD. After graduating, Andrea worked for four years at the School for Visually Impaired in Cluj-Napoca with three of those years at the deafblind unit. With a Masters degree under her belt and a major interest in supporting deafblind children she is playing a key role in the development of new services for deafblind children in Romania. She has recently written an assessment guide which is useful to teachers as well as parents.

What have I learned in these four years? It's been thought-provoking, satisfying and challenging!

I have learned to be a better person, not to take things for granted in life, to appreciate the small and simple things, to be modest.

I have learned that making mistakes is only human and it is a good thing if you admit these mistakes and you learn from them.

I have learned to be more patient than I was before. Why? Because the child has to take his time in order to understand what the teacher says and even longer to work out what he has to do and how he is going to do it. The question I have to ask myself is: "Will I still be there when the child responds?" The child does not know and understand our limited time.

I have learned that the child needs time to develop; you cannot force on him what you think he should know by this time.

I have learned that if a child does not "talk" with you, it doesn't necessarily mean that he is autistic. Children in Romania often have this diagnosis. Then, later,

after a period of building trust and understanding, after making a connection with the child, he starts to interact with you. He starts to respond and, most importantly, he starts to express himself. I like to think of this process as a number of crossings. It begins when you first meet the child and then, suddenly, you start to walk along the same road, at a certain pace, meeting along the way many landmarks and obstacles.

I have learned to look for positive things and not to search for negative results and the child's failures. You have to build on something that exists, some ability that the child has. It doesn't matter how little that is. One acquisition leads to another acquisition. It is our job to work out how these abilities are related to one another and how we can stimulate and motivate the child to develop them.

Each child who is deafblind or multi-sensory impaired is unique. As a teacher you have to adapt your methods of teaching to the abilities of the child, to be creative and to have fun. "Fun" does not mean that things cannot be serious too!

I have learned that children can learn a lot through playing and you can achieve the academic results using non-traditional methods of teaching. Theory can be very different from practice. Even though you might have a lot of theoretical information in this domain, in practice you can bump into difficulties when relating to a child and trying to work with him. In fact, you have to be a very good observer and a person who cares.

I have learned not to give up easily. Children often respond after a long period of time – when you thought that all your methods are wrong and everything was hopeless!

I learned that as a teacher we often do what is obvious and natural for us and think it must be the same for the child too. We have to consider things from their perspective. I sometimes asked myself: "Why doesn't he understand? This is so easy or this is so obvious!" But then I realise that it can be easy and obvious if I know how to make it easy and obvious for a deafblind child.

I have learned that I don't have to know everything. I only have to tune in, to communicate and just let things take their course, even though it seems that it is very difficult. Just letting go and going along with the child can be very challenging! The objectives that you set up have to be very clear, realistic and achievable in a period of time. If

our expectations are too high from the beginning, we lessen the chance for that child to achieve. Time creates opportunity and opportunity creates reaction.

It is very important to have a good relationship with the child, he must feel that you can be trusted, that you care and that you are there. The child needs to know that you are there

for him even when you are not interacting.

I have also learned that even though I made many mistakes and sometimes I was too impatient, expecting things to happen as quickly as possible, it amazes me how children are willing to forgive and forget, and love me with all my faults.

I am grateful for that.

Wanted: Conference Host

Dear friends,

Apologies to those of you who are not in Europe!

Is your organisation interested in hosting the 2009 Dbl European Conference?

It seems a long way away, but the next European Conference will be in 2005 in Slovakia – and at that conference the hosts of the 2009 conference will be announced. The process for making that decision starts now!

The European Conference is one of the major events in Dbl's programme. It takes place every four years and is usually second only to the World Conference in terms of size and number of delegates.

Full applications will need to be with the Dbl Secretary by 31st October 2004.

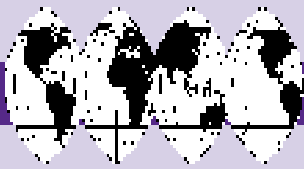
For information about how to apply and for any other information you might require at this stage please contact Richard Hawkes, Secretary of Dbl at Richard.Hawkes@senseinternational.org.uk

I look forward to hearing from you.

Very best wishes,

Richard

Richard Hawkes
Secretary
Deafblind International
11 – 13 Clifton Terrace
Finsbury Park
London N4 3SR
United Kingdom
Tel: +44.20.7561 3308 (direct)
Tel: +44.20.7272 7881
Fax: +44.20.7272 6012



East Africa

Penny May
Kamau reports:

There has been a huge amount of very successful activity over the year with parents and professionals working hard – and together – to develop new services and ways of supporting each other. There was a get-together of 40 deafblind people at Kibosawa, which was a landmark event. It was emotional moment of pride among those who worked so tirelessly to make it happen but it also underscored the magnitude of the challenge still ahead of us. Those of

us who have worked closely with deafblind people it was exciting to see the evidence of the fruits of their labour. Those deafblind people who have been part of the pioneering work interacted as adults who have acquired skills and a measure of independence in their lives, something unthinkable twenty years ago. However, there was also the sobering reality that many deafblind people still live on the periphery of mainstream society and, because of

this lack of connection, are particularly vulnerable to abuse and rejection.

Access to information for deafblind people is very poor indeed and the need is great. This is illustrated in the way in which information about the AIDS crisis has reached over 90% of Kenyan citizens, yet, something so serious as this, is not available to deafblind people because of lack of proper communication support.

Scotland

The rise and rise of the Helen Keller International Award

With more entries than ever before – 330 to be precise – the Helen Keller International Award continues to grow. Sense Scotland artist, Aidan Fox Flynn helped launch the 2004 Award at Glasgow Film Theatre on 1st December, where the promotional film about the award was shown before the main feature film throughout the entire week.

The Award will be judged this October and the Collins Gallery, University of Strathclyde in Glasgow, will play host to the exhibition

of work submitted to the competition from 8th January – 12th February 2005.

For more information about the Sense Scotland arts department contact: Lindsay Mitchell
Arts Development
Sense Scotland
5th Floor, Clydeaway Centre
45 Finnieston Street
Glasgow G3 8JU
Tel: +44 (0)141 564 2444
Fax: +44 (0)141 564 2443
Text: +44 (0)141 564 2442
email: arts@sensescotland.org.uk



Jay Townsend, Aidan Fox Flynn and Diana Fox Flynn

Graeme Thomson
from Sense
Scotland writes
about healthy
living for
deafblind people

Healthy Living for Deafblind People is a joint national project between Sense Scotland and Deafblind Scotland which is running for three years, funded primarily by the New Opportunities fund. The two Healthy Living Teams are identifying and addressing some of the current health promotion issues amongst the deafblind people they support.

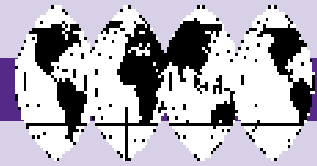
Sense Scotland's healthy living team is made up of the Senior Healthy Living Advisor, three

part time healthy living support workers and an administration worker. They bring with them extensive experience in supporting people who use Sense Scotland's services as well as an understanding of sport, health and nutrition promotion.

Initial links have been made with Sense Scotland residential and housing support services across Scotland, to highlight opportunities for accessing healthy living activities,

particularly around physical activity and healthy eating. In addition, the healthy living teams investigate individual healthy living priorities. Once baseline healthy living needs are discovered, the team can build up a clearer picture of the overall issues. Already themes are occurring and it is known that many people would like to be more active and enjoying their own local community facilities.

To address identified needs, the Healthy Living staff recently organised



Healthy Eating Awareness Days, Healthy Lunches, and Physical Activity training. Topics covered so far include: healthy living choices; the importance of eating fruit and vegetables daily; fun taster sessions and activity development; changes in eating habits. The team are aware that increasing levels of physical activity can be fun and this can make a difference to wellbeing. These sessions are relaxed occasions and give participants an insight into how to help people with congenital deafblindness, or other complex support needs, improve their health.

In addition, Deafblind Scotland and Sense Scotland are holding open, public events or Health is Fun events. The Health is Fun events are for all deafblind people, so both Sense Scotland and Deafblind Scotland service users participate in them. A wide range of activities

are on offer and everyone is encouraged to find out more about leading a healthier life. From chair aerobics and hand massages to samples of fruit smoothies and advice on healthy lifestyle choices, the work is about helping all deafblind people take steps towards improving their health.

Comments from Sense Scotland staff who attended a Healthy Living event:

"I hadn't realised how important it was to offer changes and alternatives to service users."

"I thought the day was great and I have a good diet but the information given was new and I'll be able to share it with service users."

Healthy Living for Deafblind People – overall aims:

- to improve the physical and mental health and well-being of deafblind people in Scotland
- to increase physical activity and healthy

lifestyle choices amongst deafblind people in Scotland

to provide training to essential practitioners in the wider community such as leisure centre staff, primary healthcare teams (e.g.: GP practices) and also hospital based staff

If you would like more information about this exciting project, please get in touch with us.

The Sense Scotland Healthy Living contact details are:

Maureen d'Inverno
Senior Healthy Living Advisor
Healthy Living for Deafblind People Project
Fife Sensory Impairment Centre
13 Wilson Avenue
Kirkcaldy KY2 5EF
Tel: +44 (0)1592 412947
Fax: +44 (0)1592 411761
Text: +44 (0)141 564 2442
email:
hlc@sensescotland.org.uk

Finland

Katri Pyykkö,
Information
Officer at FDBA
reports:

The 8th Helen Keller World Conference – Tampere, Finland June 2005

World Federation of the Deafblind – 3rd to 7th June 2005

In Tampere, Finland there are two major events in 2005. The 8th Helen Keller World Conference will be followed by the 2nd Assembly of the World Federation of the Deafblind.

The Conference is being arranged by the World Federation of the Deafblind (WFDB) and the Finnish Deafblind Association (FDBA). The patroness of the conference is the President of Finland Ms. Tarja Halonen.

The theme of the Conference is "Our right to be deafblind with full

participation in society".

In the programme there will be a lot of information and discussion on the human rights of disabled persons especially from the viewpoint of deafblind people.

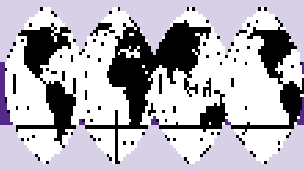
We expect approximately 200 – 300 participants. These will be predominantly deafblind persons with their interpreters, guides and assistants but we also extend a warm welcome to people working in the field of deafblindness. We hope for numerous participants to make their way to Finland to

meet and make contact with each other.

There will be a very full programme of plenaries and workshop sessions.

Plenaries will address the following areas:

- What does participation in society mean? What is the situation of the human rights of disabled people in the United Nations?
- What is happening in the European Union?
- What makes deafblindness a unique disability? We will explore the right to be deafblind



In the beginning of June the weather in Finland is much warmer than in March when the international planning group had a meeting in Finland. Stig Ohlson, the president of WFDB, was brave and swam in the lake of Tuusula. FDDB has no intention to force conference participants to swim in ice cold water, but we will offer you the chance of having a sauna and a swim in a lake – the combination that every Finn experiences, especially in the summer time. (photo: L. Holm)



and search for answers to questions like “Who is deafblind and how to recognize it? Equal participation in society. Education, professional, political, communicational rights and the right to move (mobility) are among the issues to be discussed.

The closing session of the Conference is on Sunday morning and after that the 2nd General Assembly of the WFDB begins.

The aim of the Assembly is to make official declarations and resolutions etc.

“The Assembly will take up the themes of the Conference and concentrate on the “rights agenda” for deafblind people and “recognition as an equal person before the law”. In celebrating diversity, the Conference and Assembly should empower delegates to positive action all over the world.” Lex Grandia, Secretary General WFDB

Who will be speaking?

Some of the speakers will be invited and some will be chosen from abstracts

submitted by interested parties. The last date for submitting an abstract is 1st November 2004. Preference will be given to deafblind persons to participate as speakers in plenaries and workshops, but other persons are also welcome to submit their abstracts. Acceptance or rejection of speakers will be announced in March 2005.

Who is on the planning group?

Mr. Stig Ohlson, president of WFDB

Mr. Lex Grandia, secretary general of WFDB

Mr. Daniel Alvarez, vice president of WFDB

Mr. Seppo Jurvanen, vice-chair of FDDB.

The organizing committee

Ms. Ulla Kungas, chair of the FDDB

Mr. Seppo Jurvanen, vice-chair of FDDB

Ms. Anita Palo, member of the FDDB

Mr. Kai Leinonen, executive director of the FDDB

Heikki Majava, international officer of the FDDB

Katri Pyykkö, information officer of the FDDB.

The organizing conference service is Tampere Conference Service Ltd., which is in charge of the registration process etc.

Support for delegates

Deafblind participants from developing countries can apply for support for travel costs from the conference planning committee. Applications should be submitted by 1st November 2004.

Where?

The Conference will take place in the City of Tampere in southern central Finland, 170 kilometers from Helsinki. It is an old industrial town. The conference venue is in Tampere Hall, which is located in the city centre. Hotels are closely situated within a walking distance from the conference venue.

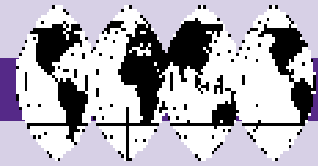
Language

The official language of the conference is English

Contact

Abstracts and applications for subsidies and other information contact:
Helen Keller Conference 2005
Finnish Deafblind Association
P.O.Box 40, FIN-00030 Iiris, Finland
Tel. +358 9 5495 3513
Fax +358 9 5495 3517
E-mail contact@helenkeller2005.com
www.helenkeller2005.com

For issues concerning the WFDB General Assembly, please contact the World Federation of the Deafblind:
WFDB c/o FSDB
SE-122 88 Enskede, Sweden
Tel. +46 8 39 9155
Fax +46 8 659 5042
E-mail stigohl@algonet.se, lotta@wfdb.org
internet: www.wfdb.org



Switzerland

Stefan Spring,
Swiss National
Association
for the Blind
SZB, Zurich,
Switzerland,
reports:

The Users' Forum: The deaf-blind help shape our counselling services!

The counselling services for the hearing or visually impaired and the deafblind in Switzerland are managed by the Swiss National Association for the Blind (SZB). All in all 28 people work as social workers, rehabilitation trainers or in the area of leisure activities for around 350 deaf-blind people. 54% of the deafblind people live independently, either on their own or together with a partner or their families, while 46% get support and live in a home or a home for elderly people. The SZB counselling services provide visiting services in Switzerland in addition to 4 to 5 specialized homes which either take care of deaf-blind people exclusively or have a specialized ward.

Every year the SZB counselling services carry out a written anonymous survey among its hearing, visually impaired and deafblind clients. The questions focus on satisfaction with the services provided. However, we do not find these surveys very helpful. According to the surveys, approx. 98% of the clients are generally satisfied with the services provided. Therefore, it does not help us to improve our work. We assume that many clients heavily depend on our work and that they therefore hardly dare criticize us in written form. Furthermore, dealing with written texts is in itself a challenge for our clients.

In the last three years we have gained experience with a different form of cooperation with our clients, i.e. a platform we call "Users'

Forum". Hearing or visually impaired and deafblind clients from all over Switzerland participate in the meetings of the Users' Forum organised by the SZB counselling services. The Forum expressly concentrates on improving the services which our counselling services offer. About 15 hearing and visually impaired or deaf-blind people meet twice a year in one-day meetings.

In the first part of the meeting the management of the counselling services informs the users about staff changes, new ideas regarding services or important changes in respect of financing or legislation. The people attending the Forum may comment on this information or they may ask questions relating to any area of the counselling services. They may talk about their experiences, point out mistakes, voice criticism or pay compliments and ask the management questions. If the management of the counselling services is unable to reply to these questions straight away, a statement for the following meeting is prepared.

In a second part of the meeting one or two concrete subjects are discussed. A specialist or a deafblind or hearing and visually impaired person introduces the subject. Thereafter the Forum's users may express themselves freely and talk about their expectations. The following subjects have been discussed recently:

The tasks of a social worker

The discussions have shown that many clients are cautious in their comments about

delicate subjects regarding counselling (e.g. diseases). The social workers need to behave discreetly and at the same time listen carefully and decide when they should treat a subject in further detail. The clients encourage the social workers to ask a second deafblind or hearing and visually impaired person to assist. This is especially helpful where parents of deafblind children are concerned. Moreover, the counselling services were asked to think about how emergency situations can best be dealt with and to give those concerned more security when they have to deal with unexpected difficulties.

New technical aids for the deaf-blind

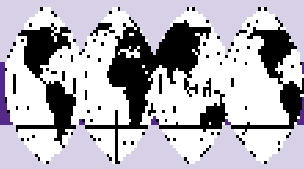
The discussion centred on how best to inform the people concerned about new technical aids. As a result, the counselling services now publish a newsletter, in which all people concerned are informed.

The hearing and visually impaired and deafblind at international congresses

The clients wish to be regularly informed about impending congresses and the results of them. Furthermore, the clients want the SZB to take care of part of the costs resulting from attending a congress.

Guide-helpers

In Switzerland there are no professional support services. However, we have more than 150 volunteer guides and this support is much appreciated by



our clients. Nevertheless, they have pointed out that volunteer work has its limits and that it is very annoying if, for instance, you cannot find anyone to accompany you on an important trip. They clearly demand paid support. The counselling services and the organisations of the hearing and visually impaired and deafblind have become

politically active in this respect.

These are just a few of the subjects we have discussed. At the end of every meeting we agree on the subject to be discussed at the following meeting.

The Users' Forum has helped a great deal to improve cooperation with the people concerned in

Switzerland. We find that this form of granting a say to the hearing and visually impaired and deafblind is much more successful than written enquiries and we would like to warmly recommend this method to other countries.

Contact person for SZB: Catherine Woodtli, email: szb.tbbl-cw@zugernet.ch

Australia



Mike Steer reports:

A New Deafblindness Service for New South Wales

The Royal Blind Society of NSW (RBS) has recently established a Deafblindness Service, funded by the State Government's Department of Ageing, Disability and Home Care. The service is currently being designed to meet the specific needs of adults who are deafblind.

The service will be staffed by specialists and will provide communication training for clients and their key support people. However, training in Auslan, (the national language for Australians who are Deaf), is not included in the catalogue of offerings. Program focus will include the following:

- activities of daily living training
- information access training
- provision of emotional and social support
- provision of training programs for professionals working with people who are deafblind

Currently the service target group is limited to between 8 and 10 adults. Specific eligibility and priority criteria exist. Enquires can be made to Alyshia Hansen or Christine Cummins: Phone Sydney, Australia (02) 9334 3222 or TTY (02) 9334 3260

A New National Symbol for Deafblindness in Australia

The Australian DeafBlind Council (ADBC) has agreed that the starfish should become the symbol for deafblindness in Australia. People with deafblindness are invited to send in their designs for the symbol to the committee to decide the finalists. The symbol must be simple and could feature one or two starfish. The final designs will be displayed on the ADBC Web site and people with deafblindness will be invited to vote to choose the winning design. Here are some of the reasons why the starfish was selected as the symbol:

- The starfish makes contact through vibrations and sensations with no vision or hearing as such. A "star" shape is a positive symbol.
- Five "fingers" that could symbolize the hand and touch, which are so vital for most people with deafblindness (two starfish together would symbolise contact and touch).
- It's simple shape is conducive to lots of possibilities.
- Starfish are popular creatures – especially among the younger crowd.

How often have you seen kids so excited when they find a starfish while beachcombing. Starfish merchandise would be attractive to a wider audience. So there is potential to distribute some wonderful products during Deaf Blind Awareness Week in association with a designer and major supermarket or department store e.g. starfish pens, badges, brooches, rub on tattoo, beach bags or mini backpacks with starfish on, bumper stickers, t-shirts, hats.

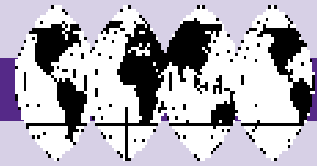
Starfish can move their arms so have a human-like appearance. Many delightful themes for events (beach, water, underwater) can be attached to the starfish.

Entries must reach ADBC by 30 June 2004.

The address is: ADBC, PO Box 1213, Camberwell Victoria, Australia 3124

Australian Federation of Disability Organisations (AFDO)

This new voice for people with disabilities is currently being registered with the



Australia continued

Australian Securities and Investment Commission as a legal entity. When finalised, AFDO (<http://www.pdca.org.au/AusFedOfDisability.html>) will replace the current National Caucus of Disability Organisations. The first full members of AFDO are:

- Australian Association of the Deaf
- Blind Citizens Australia
- Brain Injury Australia
- Deafness Forum
- National Council on Intellectual Disability
- National Ethnic Disability Alliance
- National Indigenous Disability Network
- Physical Disability Council of Australia

Good News from Western Australia

Good news travels fast, so many readers may already know that Senses Foundation (WA) has won the bid to host the next Deafblind International World Conference in Western Australia in 2007! So start saving your pennies.

We are hoping for visitors from all over the world.

Deafblind Childrens' Network Launched in New South Wales

A new Network and support group has been established for families of children who are deafblind. The Network and support group will provide communication advice, guidance, support, recreational outings, and deal with issues relating to children who are deafblind.

With the help of the Deafblind Association (NSW) the group will attempt to improve service delivery through seminars and workshops and regular newsletters. Plans are ready to start a parent and family page on the web.

There is no other support group of this nature in NSW.

For more information please contact:
Deafblind Association (NSW)
P.O. Box 1295, Strathfield

N.S.W. 2135
Email: dbansw@gpo.com.au
Website: <http://www.dbansw.org.au>
Carolyn Ferguson – Parent Rep DBA (NSW)
Email: herger@optusnet.com.au

The 7th National Australian Deafblind Conference 2–5 July 2004

The Deafblind Association (Victoria) is proud to host The 7th National Deafblind Conference, which will be held from the 2–5 July 2004, at Rydges Riverwalk – Melbourne.

Conference themes are:
Friday-Sunday, 2–4 July
– “Deafblind and Moving On”.

Monday, 5 July “Disability and Moving On”.

Enquiries can be directed to Annie Rose:
Phone: (03) 9824 4288
Email: arevents@netspace.net.au

India

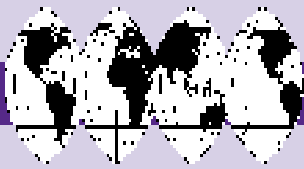
Subash Detrange from the Association for Blindness and Low Vision reports:

The past year has witnessed steady growth and development at the Association. Just a taste of our activities include:

- a study on the Human Rights of Blind and LV people in the countries of the Asian Blind Union is now available from the office of Secretary General ABU;
- an evaluation of the implementation of the Persons with Disabilities Act in Maharashtra is called ‘Let Facts Speak for Themselves’. Copies of the Report were submitted and sadly the performance

of the Maharashtra Government was rated as ‘poor’; the Association produced an 83 page Directory on Funding Agencies in the Disability Sector. A large number of copies have been sold already. Encouraged by this response the ABLV proposes to bring out the second addition shortly; ABLV has been requested to adapt and produce in Braille / Large Print IEC Material on HIV/AIDS by Mumbai District Aids Control Society with a view to creating awareness of

the killer disease among persons with vision impairment. This project has just been completed; the Association is developing safety instructions in Braille and Large Print on the request of Jet Airways Mumbai, for Blind and Low Vision passengers.



Romania



Romania recently held an Evaluation Seminar relating to the Training Course for Teachers, which was established by the Romanian national Inspectorate and has been running for the past 18 months. The course was designed specifically to prepare staff to work with deafblind and multi-sensory impaired pupils and was undertaken under the auspices of a unique co-operation agreement that exists between Sense

International (Romania) and the Romanian Ministry of Education and Research.

The training course, with a total of 112 hours of study, took place across two years with taught and self study components. The faculty were a team of Romanian and UK staff who were brought together to develop the programme. Twenty seven very happy teachers received their certificates of completion at a lively event in Bucharest this spring.

The event was received with enthusiasm by Inspector General Mr Mircea Vlad and Inspector General Simona Nicolae from the Ministry of Education and Research, who personally attended the seminar along with inspectors and headteachers from all over the country. They joined Richard Hawkes, Cristiana Salomie, and Norman Brown, who coordinated the training from the UK, to celebrate this success.



making the **invisible visible**



**6th Dbl European
Conference
on Deafblindness
2005**

2-7 August | Prešov | Slovakia

1st Announcement



Slovak Deafblind Community

Location

The conference will take place in Prešov, a beautiful historic town in the region of Eastern Slovakia. The conference will be held near the centre of the town. A variety of hotel and student hostel accommodation is available within walking distance.

Transportation

There is an international airport in Košice which is 40 km from Prešov. Bus and railway connections from and to the surrounding countries are available in Prešov.

Language

The official language of the conference is English.

Dates to remember

May 2004

Mailing of the second announcement and the call for papers

November 2004

Deadline for submission of papers

February 2005

Notification (acceptance or rejection) to submitted papers

2 -7 August 2005

6th Dbl European Conference on Deafblindness

**Secretariat
of the conference**

A&D Global Business Relations, s.r.o.

Attn. Anna Mišinová

P. O. Box 208

Nám. legionárov 5

080 01 Prešov

Slovakia

phone: +421 51 7582 485

fax: +421 51 7582 485

e-mail: conference@dbiconference.sk

For more information about the conference, please, visit our web site

www.dbiconference.sk

Dbl

Deafblind International (Dbl) is the world association promoting services for deafblind people.

www.deafblindinternational.org

5th European Seminar of the Acquired Deafblindness Network

“Expectations, Opportunities and Possibilities”

Exploring the relationships between people within the World of Acquired Deafblindness

29 October to 2 November 2004, Harrogate, UK

Due to circumstances beyond our control the venue and date for the conference has been changed

Theme: This seminar will review the relationships between people in the World of Acquired Deafblindness. We will be exploring ways to improve services to people with Acquired Deafblindness.

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

The Acquired Deafblindness Network: The Acquired Deafblindness Network is recognised by Deafblind International (Dbi) and was established in 1989. Its aim is to create and support a network of people who are involved in the World of Acquired Deafblindness. For this reason, a seminar about ‘Acquired Deafblindness’ has been held every two years in a different European country since 1994.

Sense: Sense is the national deafblind charity that supports people who have both hearing and sight difficulties. Sense offers a wide range of support and services across the UK to help deafblind people of all ages to reach their potential. This includes advice, support and information for people who have developed hearing and sight loss in later life.

Conference & Accommodation

Venue:

Harrogate Moat House
Kings Road
Harrogate
North Yorkshire HG1 1XX
UK

Costs:

£655 per delegate

This is inclusive of:

- Conference fees
- 4 nights accommodation in a single or twin room
- All meals

The complete seminar programme and registration form will be available in May 2004

Sense East
72 Church Street, Market Deeping,
Peterborough, Cambs, PE6 8AL, UK
If you require this information in another format or further details please contact: [Tracey Cook](mailto:Tracey.Cook@sense.org.uk)
tracey.cook@sense.org.uk

Telephone: +44 (0) 1778 382230

Textphone: +44 (0) 1778 382266

Fax: +44 (0) 1778 380078



John Makes Toast

Gillian Morbey. Chief Executive Officer, Sense Scotland shares her thoughts about the value of arts programmes for deafblind people and highlights 'Expression Unlimited' which involves deafblind people from all over Europe in performance arts!



I have had the great privilege of working in our wonderful field of deafblindness for nearly 30 years. Over this period I have made some observations. In this article I would like to share a few thoughts around the use of art as an approach to working with deafblind people.

I saw that many deafblind children and adults, while they had skills, didn't seem motivated to use them. John knew how to get up, dress himself and make his morning cup of tea, yet every day was a struggle.

Not so many years ago we used to keep targets for John, checking that he was undertaking tasks and, when he achieved those, we would add another one. Our support to John was task orientated and measured in targets.

I knew I didn't lead my life this way. My life was not driven by target setting and measuring my success. Sometimes I could even move on to new areas without fully mastering old ones. How then does the way we used to support John fit into the growing philosophy of inclusion and ordinary lives?

Perhaps more to the point, the approach didn't really seem to be helping John. He didn't appear to be happier or more motivated. Yes he had skills, but on many occasions he didn't want to use them. In fact, sometimes he would actively work against using them.

Over the course of my career I have heard various views on this. They are usually expressed along the lines of "rubella children are difficult to motivate", "it is so difficult to find the key to deafblind children", "he's not really interested in much" etc.

My original professional career had been in nursing and over that period I worked in a psychiatric hospital. Here I saw many people with mental health issues including depression. Patients were hard to motivate, they were disinterested. Put simply if you don't have a sense of your own value it is hard to be interested and active.

Now I am not suggesting that deafblind people are all depressed, although there is every reason to suppose that some deafblind people do suffer from depression. We know that to have this fully

investigated, diagnosed and treated would take a great deal of time as the medical profession are still not geared up to support deafblind people. We will, of course, continue to work alongside our colleagues in health to improve our understanding and treatment; however that is the subject of another article.

In the meantime people like John were no further forward and seemed to lack a sense of wellbeing and self esteem. There was a clear need to support John now and not wait until all the professionals had caught up with him.

Art seemed an immediate and simple area to start with. This was purely intuitive. The thinking behind this was:

People cannot be included unless the individuals concerned have a sense of worth and value. Deafblind people may experience a

'Expression Unlimited' performers





Ross with arts worker James working on a wooden train

low sense of worth and self esteem and involvement in the arts seems to help develop confidence and a sense of value.

Deafblind people are excluded due to their lack of access to information and the challenges they face in communication. Most arts programmes can transcend the need for verbal communication thus levelling the playing field. Drama, music, painting and sculpture can all be nonverbal. These activities can place deafblind people on an equal basis. Think how you enjoy music for example, it doesn't have to have words for you to experience an emotional response. Music can make us laugh, cry and dance.

Many deafblind people find it difficult to express themselves and again the arts offer a rich resource for expression and communication.

Moreover, in our own programmes, we discovered a surprise benefit. We had real concerns that mainstream artists would not be able to communicate with deafblind people. However we found that this fear was unfounded. The art tutors found their own ways to communicate and it could be argued that they bring freshness to working with

deafblind people that may have been professionally 'trained out' of some of us. This short article can't explore this thinking further but I would be interested in the opinions of my colleagues in this respect.

We were not alone in this thinking and we could see that other organisations in different countries were also developing arts programmes. In discussion it was soon obvious that we have much to learn from each other. Some of us are more advanced in drama, some have had great success with woodwork, sculpture, painting etc.

I am not suggesting that arts is the whole answer for everyone, however I do think it is an important approach that has much to offer. Everything an educationalist might want to teach can be done through the arts. Communication, turn taking, colours, fine and gross movement, fun and group work, to name but a few.

Given that a number of countries and organisations were engaged in aspects of this work, it seemed absolutely right that we should start to work across countries and that's where we are now. Art, of course, also crosses cultural divides and language.

We are learning a lot through a recently funded European project 'Expression Unlimited'. Here we see that performers (in this case deafblind people) are at the centre. They are not just participating; they are in control and leading.

It is still early days for us, but a number of countries are meeting in Italy at the end of May 2004 to write and rehearse a performance with deafblind people, assisted by our Artistic Director. When we leave Italy we will be assigned our parts, which we will practice when we return to our own countries. We will meet for another week in Scotland in September concluding with our first live performance in a main Glasgow theatre.

If the project is a success, and we can extend the funding, other countries may join us and who knows – we might establish the first group of touring deafblind artists. We might perform in Slovakia in 2005 but you will need to book early as we could be sold out!

Finally we found that painting was a key for John. The morning rituals are not so difficult for him now and he even makes toast with his morning tea.

Gill would like to extend her thanks to all the participating individuals and countries. Particularly William Green, without him the Expression Unlimited project would not be a reality.

If you would like to find out more about Expression Unlimited please contact:
Gill Morbey
Sense Scotland
45 Finnieston Street, G3 8JU
Tel: 00 44 141 564 2444
E-mail: gmorbey@sensescotland.org.uk

Europe recognises deafblindness as a distinct disability



Lucy Drescher reports on her work joining friends and colleagues across Europe that led to this ground-breaking decision!

A historic Written Declaration on the rights of deafblind people was formally adopted by the European Parliament on 1st April. This was the culmination of a long campaign by deafblind people, families and professionals in Europe.

The Written Declaration is a 200 word statement about the fact that deafblindness is a distinct disability. It lists the rights to which deafblind people should be entitled.

EDbN (European Deafblind Network) has been working for some time with Richard Howitt MEP, Chair of the Disability Intergroup in the European Parliament, on a campaign to get deafblindness recognised as a separate disability at the European level. Sense, as a member of EDbN, has been leading on this campaign.

May 2002

Mr Howitt spoke at the Social Inclusion seminar organised by Sense International, Lega del Filo D'Oro and Casa Pia de Lisboa and attended by many EDbN members. He promised to support the Charter for deafblind citizens of Europe.

2003

Following up on Richard Howitt's promise I went to Brussels in July last year to

meet Richard and Sophie Beaumont from European Disability Forum. Richard and Sophie were both very keen to work with deafblind people and get deafblindness recognised at the European level. It was agreed that recognition of deafblindness at a European level could be used, as appropriate, by people in the various member states to persuade their governments to give deafblind people the rights they need to play a full part in society.

January 2004 – Brussels

A reception and an exhibition were held in the European Parliament in the first week of January to launch Written Declaration 1/2004. Richard Howitt MEP, Mario Mantovani MEP, Liz Lynne MEP, Ilda Figueiredo MEP and Patricia McKenna MEP submitted

this declaration on behalf of EDbN.

The reception hosted by Richard Howitt was held with the Disability Intergroup of MEPs in the European Parliament on 6th January 2004.

Deafblind people from Belgium, the Netherlands, the UK and France gathered in Brussels for the evening with representatives of organisations Sense, Lega del Filo D'Oro, CRESAM, anspa, APASCIDE and spermalie. Over eighty people, including ten MEPs attended the very successful event. William Green from Italy spoke on behalf of DBI (Deafblind International), in his position as President and Wolfgang Angermann from Germany spoke in his position as Acting Chair of EDbN. Peter Vanhoutte from Belgium spoke about





his personal experiences and why recognition of deafblindness is important to him. All of the speakers welcomed the Written Declaration and encouraged MEPs to sign up to it, saying that even if they did not believe in it, many of their constituents did very strongly!

In the same week an exhibition was held in the European Parliament. Photos of deafblind people from across Europe were displayed along with

information about the organisations that are members of EDbN.

The Countdown!

The declaration was available for MEPs to sign up to for three months from 12th January until 12th April. EDbN members spent these three months endlessly emailing, faxing, writing to and phoning their MEPs, telling them about their personal experiences of deafblindness.

The easiest time for

MEPs to sign up to written declarations is when they are in Strasbourg for the plenary sessions, because all the declarations are available just outside the chamber. In March I went to the two Strasbourg sessions and stood outside the chamber holding up a poster to remind them to sign the declaration! Aside from getting very tired feet, this gave me the opportunity to meet many of the MEPs and remind them to sign the declaration when they might otherwise have rushed past without signing.

I was in Strasbourg on 1 April and as the voting was coming to an end we still needed 5 signatures! With the assistance of Liz Lynne MEP the last few MEPs were persuaded to sign and the declaration was adopted with 323 signatures, which was more than half of all the 626 MEPs. This meant that the Declaration was formally adopted by the plenary session of the European Parliament in the afternoon of 1st April.

The adoption of this declaration is a very important success for deafblind people all over Europe. We could not have achieved this success without deafblind people, their families and professionals across Europe working together to lobby their MEPs by emailing, faxing, phoning or writing to them asking them to sign up. This is only the first step – now that we have begun to work together we can ensure that the voices of deafblind people are heard throughout the European Union.



DbI Members responded to the successful EU Campaign with these messages!

Over a year of dedication and hard work have produced a victory for this task force, and I want to thank those who have excelled in their efforts: Lucy, our captain, Sue, Malcolm and Richard, William, Wolfgang and Martin Pav- who proved to be an expert sprinter over the last 100 metres. Definitely I also want to include in my words of gratitude Sense who led the campaign and EDbN who provided us with a European dimension.

This is for me a unique opportunity to declare that we can and must continue the teamwork on the European level.

We, the Catalans, invite you all to Barcelona for a celebration with 'cava' (our 'champagne')!

Kind regards,
Ricard Lopez
Catalan Countries & Spain

Congratulations and many thanks to all of you!! I am really glad with our result. In fact I have never been that happy as today. Let's all drink a deafblind drink.

Cheers!
Peter vanhoutte

This result is excellent!! I like to say "thank you so much" to Lucy for her tremendous outstanding struggle to get the necessary number of signatures, and I also like to say that EDBN appreciates with deep gratitude the valuable support Lucy has received from Sense International, from her colleagues at the organisation, and, last but not least, from the DBI President. We can be proud of this success we have achieved.

With best wishes
Wolfgang

Dear friends

We did it – we really did it! It once again shows what a power we have, when we have to fight for the cause deafblindness. A brilliant job – thank you very much.

Kindest regards.
Danish Parents Organisation
Lone

Congratulations to the whole team on achieving this great success!

Well done!
Akhil Paul

Hi Everyone,

Just to add to what has been said. This is wonderful news and huge congrats to all those involved for such brilliant work.

Kindest regards from everyone at Sense Scotland.
Gill

Lex Grandia sends his warmest summer greetings to everyone ... as he writes this letter ...

It is an honour, but also a lonely job I am doing at the moment. As Secretary General of the World Federation of the DeafBlind, I get more and more involved in United Nations activities. It seems to be the right time. Many doors in the different UN organisations are slowly

opening after the General Assembly adopted the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities in December 1993. In 2001 the UN General Assembly adopted a resolution to appoint an ad hoc committee, consisting of all national representatives, to

draft the text of a convention on the rights of persons with disabilities.

The ad hoc committee met twice for 2 weeks and the final result of the negotiations were that a smaller working group was elected, consisting of 27 national representatives and 12 representatives



of international disability organisations. I am part of this working group, representing the World Federation of the DeafBlind.

The working group had its 2 week meeting in January and managed to write a draft report to present. This committee will have another four weeks of meetings and negotiations, so many things can still change!

I want to share with you my experiences until now. I hope it will give you something to think about.

Recognition of deafblindness

It became clear quite soon, that the group, during the meeting, spoke two different languages! The national representatives, many of whom were lawyers, spoke a more legal language, whereas the disability organisations spoke a more affirmative language. The lawyers were afraid of spelling out new rights, that were not already formulated in other existing conventions. The disability organisations had to press hard to even get the right to an accessible environment and accessible information and communication through.

Some delegates demanded a definition of disability, whereas others thought that it was dangerous to have one. A definition can also be used as a weapon against us.

The same happened with mentioning disabilities, like blindness or deafness or deafblindness. For example, if we say, that sign language should be recognised for deaf people, we exclude other groups who are also using sign language. There can also be disabilities and syndromes that we don't

know about yet. They would be excluded too.

Convention and Standard Rules

We also found out the difference between a Convention and the Standard Rules. The Standard Rules are guidelines for states to develop services. Deafblindness is mentioned here. In the supplement to the Standard Rules, which is now in the process of adoption, deafblindness is mentioned even more. The fight to get deafblindness recognised as a unique disability is a political fight. A Convention goes further than that. It should be a strong document that has an international legal basis. That is why the "freedom of expression" became a very important issue for me. The right to have your own language is not an existing right, but the freedom to express yourself in your own way (thinking about sign language and tactile communication) exists. There will even be a definition of language where tactile communication is mentioned. This is as far as I got!

Education for all

Another very hot issue became education. The so-called "inclusive education" has got warm supporters among national delegates and among other disability organisations. Here, the World Blind Union, the World Federation of the Deaf and the World Federation of the DeafBlind had to stand up and fight for the special needs which blind, deaf and deafblind people have. For many, special education was connected to

institutions, where disabled people are usually locked up and excluded from society. Institutionalisation should be avoided, but it should be recognised that deafblind people have their own particular communication, information and mobility needs. We will have to fight hard, also in other UN bodies, to keep special education mentioned as a possibility for those who need it.

There are many other questions too ...

What about the right to life? Does that also include the right to survive, thinking about the quality of life of deafblind people?

Does the right to accessibility also include the right to have access to clean water?

How much is healthcare connected to rehabilitation? Do we have the right to rehabilitation?

What about the family? Employment? What about a reasonable standard of living?

All these issues will be discussed in the future.

I hope next time to be able to present a draft Convention, that will become a legal instrument to ensure the right to all services needed by deafblind people.

Lex Grandia
Secretary General of the
World Federation of the
DeafBlind
Snehvidevej 13
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Denmark
Phone: +45 98 19 20 99
Fax: +45 98 19 20 57
Mobile: +45 23 26 91 52
Email: lex.grandia@mail.dk

CONFERENCE NOTICE



International Council for Education of
People with Visual Impairment (ICEVI)
(17-19 November, 2004)

Deafblind International (DbI)
(20-21 November, 2004)



2nd Joint ICEVI–DbI Asian Conference

Organised by: ICEVI Nepal Network

FIRST ANNOUNCEMENT

Welcome to the Himalayan Kingdom of NEPAL, the land of Yak & Yeti, the abode of Mt. Everest

Venue of Conference

Nepal Administrative Staff College, P.O. Box: 2152, Jawalakhel, Lalitpur, Near Kathmandu, Nepal

International Council for Education of People with Visual Impairment (ICEVI) is a global association of individuals and organizations that promotes equal access to appropriate education for all visually impaired children and youth so that they may achieve their full potential. It aims at ensuring access and full participation in education; promoting and assisting in building of local capacity; collaborating with local networks to ensure sustainability; providing appropriate information and building an appropriate and sustainable structure for itself. For more information on the ICEVI, visit website at www.icevi.org

Deafblind International (DbI) is the world association promoting services for deafblind people. It brings together professionals, researchers, families, Deafblind people and administrators to raise awareness of deafblindness and to campaign for the rights of deafblind people of all ages to have a good quality of life. Its membership is open to organizations, institutions, networks and individuals. Its core activities. For more information on DbI www.deafblindinternational.org

2nd Joint ICEVI–DbI Asian Conference

Encouraged from the success of first Joint ICEVI–DbI conference, the ICEVI as well as DbI have decided to organize the second Joint ICEVI–DbI Conference amidst scenic beauty of Himalayas at Lalitpur, on outskirts of Kathmandu in Nepal. The ICEVI West Asian Conference will be held during 17–19 November followed by the DbI Conference on 20–21 November, 2004.

Themes of the Conference:

ICEVI Conference – Inclusion “Right” Approach
DbI Conference – Deafblindness – Breaking Barriers in Asia

Host Committee: The ICEVI–DbI Host Committee will be chaired by Dr. L.N. Prasad with Mr. Madhav Ariyal, Member Secretary and Dr. Bhushan Punani as Organizing Secretary. The members of the Committee include Mr. Rajan Bahadur Raut, Prof. Dr. Rakesh Prasad Srivastava, Mr. Krishan Prasad Bhattarai, Mr. Janardan Nepal and Mr. Shyam Sunder Sharma (All from Nepal); Mr. Gopal Krishna Aggrawal (India) with President and Secretary General of ICEVI as well as Secretary of the DbI as Ex-Officio Members.

Scientific Committees: The ICEVI Scientific Committee will be chaired Dr. M.N.G. Mani. The members include. Mrs. Manju Samaddar (Bangladesh), Mr. T.D.T.L Dhanpala (Srilanka), Dr. S.R. Mittal (India) Mr. Kumar Thapa (Nepal), The DbI Scientific Committee will be chaired by Mr. Akhil S. Paul. The other members include Mr. Sigid Widodo (Indonesia), Ms. Punitha Kovindaraju (Malaysia), Ms. Suwimon Udom (Thailand), Ms. Milagrous Wayno (Philippines), Mrs. Indira Shrestha (Nepal), Mrs. Sheila Sinha (India), Ms. Yolanda T. Capulong (Philippines) and Mrs. Vimal Thawani (India)

Resource Mobilization Committee: The ICEVI Committee will be chaired by Secretary of the ICEVI, Mrs. Nandini Rawal with Ms. Grace Chan as Advisor and Ms. Indira Srestha (Nepal) as member. The DbI Committee will be chaired by Secretary of the DbI, Mr. Richard Hawkes with Ms. Binali Suhandani (India) and Mr. Shyam Sundar Lal Kachhapati (Nepal) as members.

Registration: To enable the participants, especially the educators of children with visual impairment and/or deafblindness, the organizers have kept very reasonable registration fees.

Only ICEVI: US\$ 80
Only DbI: US\$ 50
Both ICEVI & DbI: US\$ 100

All educators, professional workers, family members and volunteers of the visually impaired and deafblind may send duly completed registration form through email icevi-dbiasia@sparsh-india.org. Visit the conference website at www.sparsh-india.org/asianconference for further details.

Accommodation: The Host Committee is planning to provide hostel accommodation on the campus of the Nepal Administrative Staff College itself on a single occupancy, twin sharing or group sharing basis. The Hostel charges will vary from US\$ 2 to 5 only depending on sharing arrangement. The Committee would also provide hotel accommodation near the venue of conference on twin sharing basis with the tariff of US\$ 12 upward.

Paper presentation: Please send your Abstracts on the suggested Areas /Topics to the concerned Chairperson in the suggested format before 31st July 2004.

For any further information please contact:

Member Secretary: Mr. Madhav Prasad Ariyal, Country Representative, ICEVI Network Nepal, GPO Box: 12687, Kathmandu, Nepal. Phone: 00977-1-4494906 (O) 4460015 ®.
E-mail: glap@htp.com.np
Organizing Secretary: Dr. Bhushan Punani, Executive Director, Blind People's Association, Jagdish Patel Chowk, Surdas Marg, Vastrapur, Ahmedabad-15, Gujarat, India.
Phone: +91 79 26303346/26305082/26304070,
Fax: +91 79 26300106. E-mail: blinabad1@sancharnet.in
Chairman Scientific Committee (ICEVI): Dr. M.N.G. Mani, Secretary General, ICEVI, IHRDC Campus, Ramakrishna Mission Vidyalaya, Coimbatore - 641020, India. Phone: +91 0422 2697530.
Fax: 2692353. E-mail: sgicevi@vsnl.net
Chairman Scientific Committee (DbI): Mr. Akhil Paul, Director, Sense International (India), Row House No. E-II, Tarun Nagar Part-II, Gurukul Road, Memnagar, Ahmedabad-380 052.
Telefax: +91 79 27492185. E-mail: info@senseintindia.org

WE LOOK FORWARD TO SEEING YOU IN NEPAL IN NOVEMBER



Dbl Council establishes Policy Development Sub-Committee

Malcolm Matthews, of Sense, is Chair of this new group and describes its role

As part of implementing its strategy for the development of Deafblind International and promotion of deafblind services, Dbl Council has decided to set up a Policy Development Sub-Committee. Joining me on the Group are Stan Munroe (Canada), Mike Collins and Bernadette Kappen (USA), Graciela Ferioli (Argentina), Dr Bhushan Punani (India) and Ricard Lopez (Spain). The Sub-Committee will report to Dbl Council.

The Context of this Committee

Development and dissemination of policy is not an end in itself. Policy development work will aim to assist and support the following activities:

- promotion of the recognition of deafblindness and the need for deafblind services
- influencing of policy makers to take account of the needs of deafblind people
- influencing funders and service providers to resource deafblind services and develop good practice.

The Sub-Committee's work will help deafblind practitioners to articulate some of the key statements that underlie Deafblind International's work. Specifically:

- deafblindness must be recognised as an unique disability
- human rights for deafblind people means meeting their exceptional needs
- exceptional needs can only be met by people with specific skills and experience
- development of specific services or modification of services to meet the specific needs that arise from deafblindness.

The processes followed by the Sub-Committee will need to include: collaboration with other

organisations working at a world, regional and international level involvement of deafblind practitioners who operate within different cultures consultation with the deafblind field at a national level especially Dbl Council (to whom the Sub-Committee reports).

The main outputs from the Sub-Committee will be:

Policy statements and materials available in writing on paper and on the Dbl website.

Depending on future resources, it is hoped that there will also be:

- Training materials and workshops or seminars on promoting recognition, development of services and quality of services.

The tasks the Group has set itself

[International Agenda for Action On Deafblind Services](#)

An initial task is the preparation of a comprehensive document covering all aspects of "social care" related to deafblindness and the provision of services to deafblind people. A second draft is being prepared and the third draft will be sent to Council members early this summer. It is written as an action orientated document. The action points can be extracted to make a separate "manifesto". Sections can also be extracted in different combinations to make position statements related to different deafblind issues that can be used at a national level within different countries.

The purpose of this international agenda on deafblind services is to provide a framework to help organizations and individuals in different countries to promote an awareness of deafblindness and of the need for services.

At the Deafblind International World Conference in 1999 the following resolution was agreed:

"Deafblind International calls on national governments throughout the world, when considering definitions of disability and descriptions of the categories of disability, to specifically recognise deafblindness. Deafblindness means a combination of visual and hearing impairment. Such recognition must be written into legislation – and should refer to the particular needs of deafblind people, which are different from the needs of people with a single sensory impairment."

This agenda provides a framework within which organizations can develop approaches and services that fit different cultures and meet the needs of different countries. It does not provide a complete blueprint for provision of services.

The agenda can be used as a tool for influencing government and key INGOs and NGOs, for promoting legislation that recognizes the rights and needs of deafblind people, and for articulating issues to the public.

The agenda could also help the development of the deafblind field as it:

- may help support decision making on deafblind services at a local and national activities
 - may help make communication and understanding easier between countries through describing key concepts and helping develop a common language
 - may help increase opportunities for partnership and collaboration will help in raising the profile of deafblindness and the need for services specific to meet the needs of deafblind people.
- Of course the agenda does not

compromise the autonomy of any organisation either by restricting its right to act alone or to work outside of the framework.

Recognition of deafblindness at a national and regional level

Detailed Case Study examples of recognition of deafblindness at a national or state level or at a regional level are also being prepared. These case studies may be useful to Dbl members in promoting recognition of deafblindness in their own countries.

Case studies are currently proposed on the following countries / topics:

- Campaigning for the European Parliament to adopt a written declaration on deafblindness
- Recognition in India
- The "Yes To Access" campaign in England and Wales
- Romania
- Recognition for educational services in some Canadian provinces
- The use of interpreters / intervenors for medical appointments in British Columbia (Canada).

If anyone is interested in preparing a paper on recognition in their own country, I would be very pleased to hear from you.

Training materials and workshops or seminars

Some guidance in using the documents and in campaigning for recognition of deafblind people's needs and promoting provision of services will also be prepared. This might involve developing and piloting a short course or preparing a session for the next Dbl conferences.

It would be useful to know from readers what the demand might be for such a course or session.

Education

Another proposed activity is working with others to agree an education policy. This might be along similar lines to the joint policy statement of the International

Council for Education of People with Visual Impairment and the World Blind Union.

For Deafblind International, a joint statement with the World Deafblind Union would be preferable to a document only adopted by Dbl. Lex Grandia from the World Deafblind Union was an important guest at the last Dbl Council meeting and as a result we hope that our two organisations will be able to work together on a joint statement.

Proposed International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities

The proposed United Nations Convention on Disability could be an extremely important instrument in achieving rights for deafblind people. We want the convention to specifically address the needs of deafblind people.

So Dbl wants to work with Lex and the World Deafblind Union to keep people in our field informed of developments and enable deafblind people, their organisations and Dbl members to influence participants at the UN. Look out for more information on this at www.deafblindinternational.org

The next steps?

A lot of effort from a lot of people will be required to undertake the tasks I've just described. We will need to develop a longer term work plan based on the strategic direction of Deafblind International and the feedback and ideas that we get from members. So, do keep in touch and help the new Sub-Committee to make a difference to the lives of deafblind people around the world.

Finally, don't forget that progress will be reported in Dbl Review and on the Dbl website.

Malcolm Matthews
malcolm.matthews@sense.org.uk



Sumitra Mishra

Management Committee News

Meetings of the Management Committee and the first meeting of the new Council was held in St Hertogenbosch, the Netherlands on 27th – 28th February 2004. There were significant discussions with respect to increasing corporate membership, Dbl publications and Dbl website and a host of other issues.

Council News

The Netherlands Knowledge Center for Deaf-Blindness and Sense International have been accepted as full members of the Dbl Council. They will be represented on Council by Christoff Marthaler and Geoffrey Ateili respectively.

Membership Fees

The Council decided to collect membership fees in Euros, due to the significant amount of money that Dbl loses in exchanging currencies. In addition, the Dbl Council meeting at Netherlands, all Council members took it upon themselves to seek to introduce new corporate members.

The official currency of Dbl is now the Euro.

All corporate members are requested to transfer the membership fee by bank account (Transfer) to the Dbl bank account rather than sending cheques or postal orders. This will reduce the work for the Treasurer, as well as saving money.

As there has been no increase in membership fees for almost five years we are asking corporates to consider increasing their contribution. An increase as small as £100 from all corporate



members would increase Dbl income by almost d4,000. We have reviewed the situation and we need the additional funds to resource our growing range of work including the Networks, the magazine and the website.

If you wish to request a full copy of the management committee or council minutes, please contact secretariat@deafblindinternational.org

The major Dbl events coming up are:

5th seminar of Acquired Deafblind Network Conference "Expectations, Opportunities and Possibilities" – 29 October to 2 November 2004. Please note that the seminar will take place at Harrogate, UK. For more details please contact tracey.cook@sense.org.uk

The second ICEVI–Dbl Asian Conference will be held at Lalitpur, near Kathmandu, Nepal. The ICEVI conference is from 17th – 19th November and the Dbl conference on 20th and 21st November.

The sixth Dbl European Conference will be held from 2nd – 7th August 2005 in Prešov, Slovakia,

The next Dbl World Conference will be held in Australia in 2007.

Membership Update

Dbl would like to express its appreciation for the continued support of the large and small

corporate members. We strongly encourage individuals to join Dbl in order to contribute to and widen further our global community in the field of deafblindness.

There are currently 614 members including 44 corporate members from 79 different countries. These include 43 members from Africa, 76 from Asia, 38 from Australia, 337 from Europe, 96 from North America and 13 from South America.

Sense Scotland has now become a large corporate member!!

This year we intend to update our database, therefore it is very important that you renew your membership as early as possible. If we do not hear from you by September 30th, we will assume you no longer wish to be a member and your details will be removed from the database.

Membership reminders for the current year have been sent to the Corporate and Individual members. All members now have a specially assigned membership number to be used in future correspondence. Please contact the secretariat if you want more details about your membership number. Encourage your friends and colleagues to sign up as individual members of Dbl.

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

Dbl Website

We are working to make the website reflect the very latest news and information on Dbl, visit www.deafblindinternational.org. We welcome new submissions to the website so if you would like to contribute or advertise an event or recent success, please send details to Eileen Boothroyd at eileen.boothroyd@sense.org.uk.

The Dbl Secretariat

The Dbl Secretariat is now based in India!

Following the World Conference in Canada Sense International was re-appointed to continue managing the Secretariat. It was felt that an even better service could be offered by moving the majority of the Secretariat work to India. Richard Hawkes remains Secretary of Dbl supported by a Secretariat in Delhi, managed by Sumitra Mishra and Parag Namdeo.

We are keen to update the information we have about you and your organisation.

If you have any queries regarding your current membership or would like to complete the membership form via email, please contact Sumitra at: secretariat@deafblindinternational.org or post your query at: Dbl Secretariat, Post Box No: 9601, Janakpuri, New Delhi – 110058, INDIA.

Sumitra Mishra

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

Non-Voting Members consist of individuals, national networks and non-subscribing Corporates. Non-voting members can contribute to the decision making process of Dbl through either a corporate member or an international network. Non-voting members will receive a copy of Dbl Review and other relevant Dbl information. Non-voting membership costs d30 a year or a discounted d100 for 4 years.

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

There are now two tiers of Corporate Membership:

Large Corporates:
Annual Fees between d3,000 and d5,000

Small Corporates:
Annual Fees between d300 and d1,500

Corporate Members can be nominated to sit on the Council.

Deafblind International Individual Membership

I would like to join DbI as an individual member

I would like to renew my DbI individual membership

Member details Membership No.

Title Surname First name

Organisation

Job Title

Address (Line 1)

Address (Line 2)

Town/City State/County

Zip/Post Code Country

Telephone no. Fax no.

(Please include country and area codes)

E-mail address:

Are you:

a deafblind person a family member a professional

Does your organisation work primarily for/with:

blind people deaf people deafblind people

disabled people other (please specify)

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

DbI Review (please check one box in each category)

A. I would prefer to receive DbI Review in:

English Spanish

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

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

Membership Fee please tick where appropriate

I wish to pay an annual membership fee of d30

I wish to pay for 4 years' membership at the discounted rate of d100

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



Corporate Membership

There are two tiers of Corporate Membership:

Large corporates

Annual fees between d3,000 and d5,000

Small corporates

Annual fees between d300 and d1,500

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

We submit an annual fee of d _____

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

Member Details: _____

Organisation _____

Representative _____

Address (Line 1) _____

Address (Line 2) _____

Town/City State/County

Zip/Post Code Country

Tel: _____
(please include country & area codes)

Fax: _____
(please include country & area codes)

Email: _____

How to pay?

In order to enable us to put your entire membership fee to use, we would kindly ask you to avoid sending us cheques as much as possible. By arranging your fee via bank transfer, we are able to keep banking charges to a minimum, thereby increasing the value of your membership fee. Naturally, for those of you who do not have access to this facility, we will be delighted to accept your fee by credit card, cheque or in cash. However, if it is really not possible for you to pay by bank transfer and you do have to pay by cheque or credit card, maybe you could do so for four years instead of just the one.

Payment method Bank Transfer Credit Card Cheque

A) Payment by Bank Transfer

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

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

Date of Bank Transfer: _____

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

B) Payment by Credit Card

Card type VISA American Express Mastercard

Card no:

Expiry date Name on card: _____

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

C) Payment by cheque

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

Please fax this whole page to 91-11-25618430 or return to: The Secretariat, Deafblind International, Post Box No 9601, Janakpuri, New Delhi - 110058, INDIA.



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