

Deaf-Blind Education

THE JOURNAL OF THE INTERNATIONAL ASSOCIATION FOR THE EDUCATION OF THE DEAF-BLIND

January — June 1988



8-year old deaf-blind twins in the USSR with their teacher, using dactylogy. (Photo: Michael S Lambert)

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Deaf-Blind Education will appear twice yearly; the two editions will be dated January-June and July-December, and publication will be early in each period.

The editor will be pleased to receive articles, news items, letters, notices of books and coming events, such as conferences and courses, concerning the education of deaf-blind children and young adults. Photographs and drawings are welcome; they will be copied and returned.

All written material should normally be in the English language and may be edited before publication. It should be sent for publication to arrive by mid-January and mid-July for the first and second annual editions.

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

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Chairman's Report

It hardly seem possible that close to eight months have passed since our very successful conference in Poitiers. The conference provided us with an opportunity for the making of new friends, renewing acquaintances, exchanging information and seeing a little of *La Belle France*. Above all it provided us with a sense of revitalization and a will to go home and solve the problems that awaited us.

It would be inappropriate to let this occasion of the first newsletter since the Poitiers conference pass without recognizing the excellent work of Jacques Souriau, William Green, Dominique Spriet and the French planning team. All those who attended the conference would, I am sure, like me to express their appreciation for the ongoing support given by the executive who took time from their busy schedules to travel and meet with the French planning committee on at least four occasions. An excellent example of co-operation which will set the criteria against which future conferences will be measured.

If you are among those who were unable to attend the 9th Conference of the International Association of the Deaf-Blind you should begin immediately to plan to attend the 10th conference which will be held in Sweden, the first week in August, 1991. The Nordic conference committee has already been formed under the leadership of vice-chairwoman Sonja Jarl.

Present plans call for a meeting of the Executive of the International Association for the Education of the Deaf-Blind and the conference committee in the first half of 1988. We hope to combine this meeting with a meeting of the Board of Directors of the Newsletter and the Constitution Committee. If you have any suggestions in any of these areas please contact your country's member of the Executive or write directly to Mr Rodney Clark, secretary-treasurer, IAEDB. Names and addresses of members of the executive, regional representatives, and the secretary-treasurer can be found on page 24 of this newsletter.

The purpose of the International Association for the Education of the Deaf-Blind is to promote the exchange of information among parents, siblings and professionals. To this end I hope that all regional representatives and IAEDB members will do everything in their power to promote the holding of regional conferences during 1989 or 1990. The planning

for the European Conference, which will be held in the UK is already under way. If all goes well, the next edition of this newsletter should contain a list of upcoming national and regional conferences. A second way that this exchange of information can be facilitated is through various newsletters that are currently being published. If you publish such a newsletter, or know of an organization, school, or other group that does, please write to the editor of your IAEDB newsletter giving the name of the publication, the name of the publishing organization, the cost for a subscription and any other information that may be helpful. I personally have found the **Sense** and the **Canadian Deaf-Blind and Rubella Association** newsletters valuable sources of information that was of a different type and often more relevant than that found in professional publications.

Congratulations are in order to Keith Watkins, past chairman of the International Association for the Education of the Deaf-Blind. Keith reports that hopefully his thesis will be published in the near future.

In closing I would like to express my thanks to the members of the executive who showed confidence in me by electing me chairman of the Executive. There are a number of very special people whose contributions I would like to recognize publicly. Ms Sonja Jarl for agreeing to serve as vice-chairman; Mr Rodney Clark for agreeing to accept the position of secretary-treasurer, and also for all his help during the Poitiers conference; Ms Lieke De Liew and Miss Christine Long for agreeing to prepare a history of the IAEDB. And last but by no means least, a very special thanks to Mr Paul Ennals who has accepted the position of editor of the IAEDB newsletter. I am sure that with his background and experience we could not have found anyone more able and qualified to carry on the fine tradition that has been developed and nurtured in Australia under the able hands of Thom Grunsell over the last 10 years.

Finally, I would like to wish all my friends, old and new, best wishes for this coming year. If there is any way that I can assist you as chairman of the International Association for the Education of the Deaf-Blind please feel free to contact me.

John McInnes, Chairman

Assessment of Vision in Deaf-Blind Individuals

If you cannot hear, your vision is even more important. Our ability to teach them well will depend upon our understanding of their vision—yet often we do not know just how much a deaf-blind child or adult can see. How do we assess them if they cannot TELL us what they see?. How can we find a doctor with the skill and understanding to discover what we need? How many eye doctors are prepared to give the time necessary to carry out an accurate assessment? At Poitiers Lea Hyvarinen described some of her techniques of visual assessment. Here we print her lecture.

I have been invited to give a short overview on assessment of vision in the Nordic countries.

Assessment of vision in deaf-blind people covers a wide range of tests and test situations. It is different at the different levels of communication so we will divide our subject into two major parts:

1. the first part concerning clients with good or fairly good language skills, and
2. the second part concerning clients with limited or no language skills.

With both groups we have a great number of individual variations of impairment of vision and hearing which have to be taken into account when planning an assessment.

1. Clients with Good or Fairly Good Language Skills

In the assessment situation we use different techniques depending on whether the client is

1. a deaf or hard of hearing person who uses sign language or lip reading, or
2. a hard of hearing person who uses auditory communication.

The assessment of the second group of clients does not differ from the assessment of normally hearing individuals except that we must be aware of the level of hearing impairment and the risk of misunderstanding.

The assessment of the first group of clients using visual communication during the examination of their impaired vision has quite unique problems and is a

THE AUTHOR

Lea Hyvärinen is an ophthalmologist working in Helsinki, Finland. Among her many research interests she has promoted the vital importance of assessing the vision of deaf children at an early age. She has examined how different lighting conditions can affect how deaf people with vision problems can function. Lea has lectured in many parts of the world, and is considered a pioneer in her field.

real challenge to the interpreter and the eye doctor.

Those of you who participated in our meeting in Bruges last summer and saw my video on assessment of vision of the deaf-blind may recall that I stressed further education of all three persons involved in the assessment situation: the client, the interpreter, and the eye doctor alike.

Many clients with reasonably good communication in every day matters do not possess concepts needed during visual assessment. There is no time for teaching on vision and on visual impairment at the time of the eye examination so we have to arrange the teaching prior to the assessment. Since there was no information available as easy reading material I have written a booklet called *Eyes and Vision* in simple Finnish, Swedish and English for the deaf community and the interpreters. All three texts are under further development. They

will be modified by individuals who use sign language as their mother tongue, and when the work is finished the texts will be available for general use, most probably next summer through our Nordic Centre.

There is also a great need to improve teaching related to eyes and vision in all schools for the deaf. We can use the written material I have just mentioned, but there is a need for specific texts and video materials for deaf children in different grades. Those of you who participated in our conference in New York in 1984 might remember that we recognized this need at that time. If anyone has developed material related to vision and visual impairment for young deaf children I would like it to be reported here. Or if you know of anyone working on this subject, please let us know.

There is a small group of very severely visually impaired deaf persons who cannot read braille and who will need the help of an interpreter in order to learn about the vision and visual impairment they have. Although the number of these clients is limited we should remember their needs, and also meet their needs by arranging weekend courses or including the teaching in the evening programmes of summer camps and other activities.

Improvements of communication during the visual assessment requires further education of both interpreters and eye doctors. This should preferably be arranged for both groups together because they have to learn to collaborate on a basis of equality and mutual understanding of each others' problems.

Again, teaching will require written material and video films. In

this field we have one video film and short text ready, which was presented in Bruges. It is available at the Helen Keller National Centre on Long Island. I can also promise some progress within the next year because the Smith-Kettlewell Eye Research Foundation has made funds available for a study of communication during visual assessment of the deaf-blind. The project was started in March 1987. Our goal is to have the first monograph on communication and examination techniques ready by the end of 1988.

Our final goal is further education of so many eye doctors that there would be at least one, but preferably two, specialists in each university hospital competent in assessment of vision of deaf-blind people.

I would like to stress three major areas of further education.

They are:

1. time and attention for communication

I guess that every one of you has experienced the frustrating situation when a highly skilled professional does not have the time needed for visual communication. It is the responsibility of the doctor to make sure that the interpreter has contact with the client before the communication starts. Otherwise there is no true communication if the receiving part is not there.

2. the readiness to rephrase.

I have called this the 3R-rule:

repeat, rephrase, redo, meaning that we first repeat if not understood, then rephrase if the content still is not clear. If that does not help it is best to redo the whole thing by asking first what the client thinks we are discussing so that we know whether we are talking about the same thing and which concepts we can use.

3. the readiness to understand visual descriptions.

Sometimes description by a few signs will require hundreds of words for complete interpretation. We will always need video documentation of some description.

Clients with Limited or No Language

(a) mobile

(b) with limited mobility

Mobility is often related to the developmental level of the client but not always; many of our clients have the double sensory impairment on top of different motor problems. Since we usually use a motor response as an indication of visual response – as a sign that the object has been seen – we are going to make serious mistakes in the assessment of this group of clients if we don't know exactly the types of motor response that the subject is able to use. So we have to know the response pattern.

Another feature typical to this group is their low activity level. If

the client is not activated before we start the assessment, visual functions will not be at optimal level.

Some other clients may be hyperactive and have to be relaxed and calmed down before the assessment. In other words, we have to create an *optimal activation level*. The activation is most often through gross motor activity but it may as well be singing or playing with a favourite toy – or whatever.

Selection of test situation is far more complicated in this group of clients than in the first group. The other neurological impairments make it mandatory that each visual function has to be observed in several different situations. Let us think on the sequence of events during testing of any visual function:

- 1 processing in the retina
- 2 transfer through the visual pathways
 - (a) over LGN (lateral geniculate nucleus) to visual cortex
 - (b) through midbrain
- 3 processing in the associative functions
- 4 decision to respond
- 5 motor response.

In order to process the information the subject must be *motivated*, he has to be able to *attend* to that particular spatial location, to direct his gaze to the object of observation, and to *adjust accommodation* or to *observe* the visual phenomena in *peripheral visual field* without looking directly at them.

All these functions should occur well coordinated, resulting in 'normal' visual behaviour. Since the

Multiple Handicap in Nigeria

Readers might be interested in some of my findings concerning the provision of educational facilities for handicapped children in Nigeria.

During my fieldwork in Nigeria in 1984 I encountered Mark, a deaf and partially sighted boy of nine, at Owerre-Olubor, a village in Bendel State, Nigeria. His parents wanted something to be done to alleviate the boy's disability.

They were anxious for their son to be educated, since as the sole male child in the family, he bore their hope for the future. Younghusband *et al* (1970) also notes similar findings in Britain of 'greater parental

concern about having a handicapped son than daughter'. This is even more applicable in a society where the gift of a male child is the most priceless than can be bestowed on any family.

The Bendel State compilation on *Rehabilitation Exercise for the Trained Disabled Persons in Bendel State 1971 - 1981* points to the fact that the visually impaired have been the most 'privileged' of the handicapped groups in Nigeria for a long time (Caulcrick, 1981), but for victims with added disabilities there is little or no hope.

From the assessment test I found that Mark was bright and educable, but he was not in school because there were special schools in the far flung villages of Bendel State. The units for the visually impaired in Bendel State are situated in Benin City, capital of the State, so

that children in the villages many miles away cannot and do not benefit from these units. Mark therefore, who otherwise would have benefitted from some kind of support and education, was left to his own fate. He did attempt for a short period to attend the village school, but the agony and torment of teasing from his schoolmates and the impatience, ignorance and lack of sympathy of the teachers made it impossible for him to continue at school.

If one considers the present scope of special education in the UK and USA, one understands and appreciates the great need for adequate special educational facilities in Nigeria as a whole and Bendel State in particular. Moreover, because the Nigerian cultures still have a fair amount of superstitious beliefs and taboos, the

average Nigerian is liable to treat people with any sort of handicap as 'cursed'; therefore those with multiple handicaps are completely written off.

Although the first school for the blind was established in Kano, Northern Nigeria in 1944 (Caulcrick, 1981), a large percentage of people suffering from visual impairment rarely receive care and support. There is desperate urgency to assist and support these individuals in their need for a decent life, and the Nigerian government needs continual reminders of this from various pressure groups (such as parents and teachers) to provide the best for all handicapped people in Bendel State, Nigeria.

Grace Okoh (Dr.)

The British Journal of Visual Impairment, Autumn 1987 (V:3)

defect may be other than visual we should always look for different explanations of unusual behaviour.

We must remember also that a subject may reach for an object without being aware of it in higher brain functions. The awareness is based on information in the lower, unattentive level. So we have to look for visually guided - directed - reach in two different situations: with and without attention.

When observing the type of reach we must not be confused by extrafoveal fixation: fixation outside centre of vision. This happens when the central part of the visual field is lost, when there is a central scotoma. Then the subject uses more peripheral vision and seems to look beside, and not at, us or the object. Yet another group, the clients with autistic features, may avoid looking at the object they are interested in.

Since there are so many misleading factors involved, it is obvious that we gain the knowledge needed for functional diagnosis very slowly over weeks or months, sometimes years.

The assessment of our group 2 clients is divided into three different parts:

1. basic objective tests by the doctor
2. observation of visual functions (video)
3. training for test situation (video).

Video recordings are going to be a powerful tool because they give the eye doctor an opportunity to see the client functioning in a relaxed and motivating environment. Analysis of video recordings together with the teacher is followed by modification of the test situation and often variation of the camera angle so that we may collect all pertinent data.

When planning the test situations we must remember the effect of posture:

- 1 lying on back
- 2 lying on stomach
- 3 on all fours, head supported
- 4 sitting alone, supported
- 5 sitting with an adult
- 6 standing

In general we have to observe visual functions in all six cardinal postures if there is any uncertainty about the optimal posture. So, for example, assessment of fixation and following may require numerous observations.

We start with the usual small fixation targets and observe fixation and following, we make special note of reaction to Styrcar balls of different sizes. If no response is seen we use larger objects, like a black-and-white doll or picture of a face or colourful hand puppets. If

they do not interest the subject we use a gold coloured surface behind large objects with good facial illumination. If these do not trigger a response we use black-light stimulation. If that isn't effective we try a large torch with a figure pasted on it and show it in different parts of the visual field in a darkened room. If that isn't interesting we observe whether the client seems to pay any attention to large light sources like windows or lamps.

Of course, every visual stimulation and training situation is simultaneously a test situation.

Since there are so many observations needed we must be prepared to work slowly and steadily and must not be disturbed by the many errors that we are bound to make. Also in this work improvement of collaboration is the key to development. Doctors and teachers, teachers' aids, speech therapists, parents/caretakers, all need to learn to collect the pieces of this puzzle of visual assessment.

I hope that this short overview gives you an idea of the present development of the field in Nordic countries. ■

Deaf-Blind Education in Greece

Sense will be hosting the next European Conference on the Education of Deaf-Blind Children during 1989. In preparation for this, a visit by Sense Director, Rodney Clark, to Greece for the First European Conference on the Education of Deaf Children, run by the European Regional Secretariat of the World Federation of the Deaf, enabled him to investigate the situation for deaf-blind children there.

The current state of affairs is not a happy one; I would have said the current level of provision, but there is none, at least from a brief investigation.

The laws governing special education in Greece are interesting. While school attendance is mandatory for able-bodied children, it is not for those with special educational needs who may therefore be kept at home if such is their parents' wish. This includes deaf children and blind children without additional handicaps. Most special education was provided by private Institutes before 1982. Then the new Socialist Government decided that the Ministry of Education should be making some provision and so new Government Schools were opened for children with a range of disabilities. They tend to be less well resourced than the schools belonging to private Institutes whose funding comes both from the Government via the Department of Social Welfare and Health and from private sources.

The National Institute for the Deaf (NID) has a number of schools throughout Greece and there is a similar, if smaller, service for blind children.

Both the Athens School of the NID and KEAT, the Athens Centre of Education and Rehabilitation for the Blind, have a few small classes for



multi-handicapped pupils, mostly those with learning difficulties or behavioural problems. Applicants who cannot achieve a certain functioning level are not accepted, and it was a matter of some concern to me, in conversations with some teachers, to receive their often unconscious assumption that such children could not be helped by schools, but were better off being kept at home as was usually the case. I did learn that a number of parents of multiply-handicapped deaf children were pressing for them to be admitted to the NID's schools. As for deaf-blind children, I could find no evidence either that there was even one placed in school in Greece, (although I did come across a blind hard-of-hearing pupil at KEAT), or that there existed a concerned parent or group of parents who wished to see this state of affairs improved.

From what I could learn, it was unlikely that deaf-blind children would be found at schools for children with mental handicap, and that any (if they existed!) would be at home.

Rodney Clark

An Experiment in Sex Education

How do you introduce Sex Education to a deaf-blind child? It is difficult enough to teach a sighted child. Different countries have very different approaches to this subject; whilst others adopt approaches that would shock people who are unaware of deaf-blind children.

At the International Conference in Poitiers in 1987, the Nordic Staff Training Centre presented a video showing how they use massage to treat sexual awareness and relaxation among deaf-blind young people. They presented an open and honest approach which aroused much discussion.

Here Beroz Vacha describes her experiments in this field in Bombay, India. 'Deaf-Blind Education' would welcome responses to this article, and descriptions of programmes in other parts of the world.

The Goal

Awareness of male and female sex – Phase 1.

Population

Boys aged 4 to 7 years.
Girls aged 4 to 15 years.

Girls are Vasu (15 years), Mary (14 years). Totally blind and profoundly deaf. Vandana (6 years) – low vision and profoundly deaf.

Boys are Lokesh (6 years) – totally blind, severely deaf. Rohan (6 years) – low vision, profoundly deaf. Chinu (7 years) – low vision, profoundly deaf.

As part of our self help skills programme, we begin with body awareness through bathing, dressing, playing, affectionate hugs etc. Since Vasu and Mary, our oldest girls are in their adolescent period and have already reached the puberty stage, we felt that their sex education must start with body awareness.

Therefore, as part of their programme 'Help your younger friends', Vasu and Mary would dress the children by putting on their shoes and combing the hair of younger boys and girls.

They know of Chinu, Rohan and Lokesh as boys because of short hair – and of men because they have learned to feel the face and feel the shaven and unshaven beard and moustache. But that is not enough. Mary is very gregarious and, like an octopus, is always reaching out and seeing through her hands and smell, and in the process, she wants to feel things more where she was unfamiliar with the object.

THE AUTHOR

Mrs Beroz Vacha is Principal of the Helen Keller Institute for Deaf and Deaf-Blind in Bombay, India. The school is described on pages 19–20.

So, as part of our 'Self Help and Help your Friends' programme, we have a *bathing hour*. Mary and Vasu both bathe these little boys and the teacher actively teaches them through touch and communication:

- 1 The difference between little boys and little girls.
- 2 The difference between a girl and young girls (i.e. Vasu and Mary as examples).

- 3 The difference between a young growing girl and a woman.
- 4 The difference between a young woman and a pregnant woman (one of our teachers is expecting).

Outward physical changes can be felt by Vasu and Mary. The latter is very quick and sharp. We have also told them that there is a small baby which is growing in the pregnant woman.

This automatically exposes them to genital organs from the age of 5 onwards for girls and boys up to 10 years.

This experiment will be in several phases and we will report to you – if you find our first phase interesting.

In the meantime, we will welcome suggestions from you.

We are also trying out a body massage therapy; but as yet we are not ready to write about it.

Looking forward to hearing from our readers.

Australia

The editorial offices of *Deaf-Blind Education* were visited just before Christmas by Mr John Finch, Executive Director of the Deaf-Blind Care Association which is located in Melbourne in Australia and which offers services within the state of Victoria. Members who attended the Poitiers Conference may remember Ruth Carlin, the Deaf-Blind Care Association's Director of Programmes.

The purpose of the Association is to represent the interests of the deaf-

blind community, to provide support services and to work for a reduction in the incidence of deaf-blindness. Its services are principally directed towards the provision of long-term residential accommodation in group homes allied to a programme of support to families. The Association have planned a dynamic programme of activities for the coming years which will see an expansion in services.

Staff have also been working closely with Dr Jan van Dijk of the Netherlands on his congenital rubella research programme.

Integration

The last half of the twentieth century will be remembered in history as a time when integration was one of the most prominent philosophical concepts and a driving social cause that was attached to education, housing, work, transportation, in fact to all aspects of living. Mainstreaming, rights of the handicapped, equal opportunity and numerous other phrases are all ways of identifying some aspect of integration as it applies to the deaf-blind.

For the purpose of this paper 'deaf-blind' refers to a person who has both a vision and a hearing loss, the combination of which prevents him or her from being adequately served by programmes for the blind, deaf or retarded. That is, a deaf person who does not have enough vision to be adequately served as a deaf person, nor enough hearing to be served as a visually impaired person. A person for whom special provision must be made to facilitate communication, compensate for reduced ability to benefit from trial and error or secondary and tertiary learning, and to promote transfer of learned skills beyond those provisions usually associated with programs for the retarded.

Initial attempts to develop a functional definition of the term 'integration' by asking professionals met with frustration. Each professional asked about integration appeared to have their own specific definition of the term which differed to a greater or lesser extent from those which had been collected before. These definitions revolved about the location of the lodging or programme, the type of lifestyle being promoted, the type of vocational programme being provided, or simply the title of the programme.

In addition to the uncertainty that surrounded the term there was also an unexpected defensiveness by some professionals. In many cases inquiries seemed to result in a response that could best be described as 'don't rock the boat'. After this initial reaction further questioning usually resulted in a definition which was somewhat limited in scope and which reflected the particular individual's background. To avoid any misunderstanding it must be pointed out that the inquiries were made in a variety of fields including special education, social services and health and were not limited solely to those who work with the deaf-blind.

THE AUTHOR

John McInnes's work in the field of deaf-blind education spans many years. Together with his wife Jacqueline he published the classic book *Deaf-Blind Infants and Children*



while Principal of the W. Ross McDonald School for Deaf and Deaf-Blind Children in Brantford, Ontario. Now John is Consultant to the Canadian Deaf-Blind and Rubella Association and Chairman of the IAEDB. At Poitiers in 1987 he was presented with the Anne Sullivan Award for services to deaf-blind education.

Various definitions

By far the largest number of responses attempted to define integration in terms of 'living in the community'. Sometimes this could simply be interpreted as living outside an institution. In many cases the term 'living' was as elusive as the term 'integration' and usually turned out to be equated with the size of the group to which the individual belonged and the type of

structure in which the group was housed. Occasionally the necessity for qualified staff was mentioned. This type of definition could be summarised as defining integration as '*A handicapped individual living outside an institutional setting in a small group (numbers varied from not more than four to a maximum of 12) with the support of trained staff.*'

Another way of defining integration seems to focus on lifestyle. In several jurisdictions this seems to be a favourite of politicians and senior bureaucrats. Integration is defined as 'living in the community' where living means implicitly or explicitly 'with little or no specialised support'. The individual has been deinstitutionalised or non-institutionalised and it is up to him or her, the family, or concerned citizens to help him or her cope by using whatever social support exists in a particular community for the general population. Such an approach is singularly unsuccessful with the deaf-blind for obvious reasons.

A third approach to defining integration is to focus on employment and recreation or leisure activities. This approach is often combined with the first approach to produce a definition which defines 'living' in broader terms and usually by example. Quoted examples ranged from: *a combination of living in a large group with nine other handicapped individuals, attending a sheltered workshop and going bowling once a week, to: having one's own apartment, holding down a job as a computer programmer and having an active social life.* People who proposed definitions of this type tended to have a stated combination below which one could not truly say a handicapped person was integrated.

A fourth approach to defining integration was basically to name a particular programme with a title

that included the word 'integrated' and to state flatly that people being served by that programme are integrated. Integration was defined by what they were doing and such professionals tended to become very defensive when asked to clarify further why their programme should be called integrated.

It was interesting to note that individuals who work with deaf-blind people seem to have given a considerable amount of thought to the concept of integration. This was particularly true of educators of the deaf-blind who were concerned with the transition of deaf-blind students into adulthood. Even here there is a wide difference of opinion between those who maintain that a deaf-blind individual cannot be truly integrated if they require support of any kind that is not required by the general population, and those who do not see such support as any more obstacle to integration for the deaf-blind than a wheelchair is for a physically handicapped person. In the majority of cases the former tended to work with the adventitious deaf-blind and the latter with the congenital deaf-blind. It is not the purpose of this paper to expand further on this particular point because the topic of 'Intervention, Its Use and Abuse' could be the subject of a major presentation in itself.

People are integrated

A meeting with a group of handicapped young people concerning another problem provided the opportunity to discuss what integration meant to them.

Their thoughtful discussion, combined with the information that had been gathered by the Canadian Task Force on the needs of the deaf-blind, provided a basis for developing a working definition of integration which could be applied to the deaf-blind.

In addition to restating the four points previously discussed it was pointed out that *people* – not work-spaces, housing or activities – are integrated, and that successful integration does not mean homogeneity. Only the cosmeticians and health clubs want to turn all women into Bo Derek and all the men into Rambo.

The handicap of multi-sensory deprivation will not be eliminated by placing the deaf-blind person in a programme designed for some other handicap, or by placing them in the community without appropriate support and pretending that if they just try they will not require special assistance to overcome their multi-sensory deprivation. A multi-sensory deprived person of any age will have

problems with communication, a unique learning style which will have been developed to take into account a severely diminished ability to benefit from trial and error, and/or secondary and tertiary learning experiences without the intervention of another person to ensure that they receive sufficient undistorted information. They will have problems in transferring previously learned skills to new situations and the problem of both self and social motivation will have to be addressed in a unique way. Any attempt to integrate the deaf-blind person into society must also take into account the unique combination of problems which each deaf-blind individual faces, and must be flexible enough to address individual needs within the broader context of an overall support plan.

In addition to location, type of programme and provision for individual differences, there are certain other elements which must be present if true integration is taking place. The deaf-blind person must have:

- access to meaningful information;
- an opportunity to make decisions;
- the support necessary to carry out the actions which result from these decisions;
- freedom of association; and
- right to change his or her mind.

The UCH/RNID Cochlear Implant Programme

At the Royal Ear Hospital, University College Hospital, London, we have had a particular interest in deafness for many years. Our research work has been helped by an association with the hospital's Physics Department and also the Royal National Institute for the Deaf.

What is Cochlear Implant?

A cochlear implant is really a special type of hearing aid intended for totally deaf people who can hear nothing with even the most powerful conventional aids. Implants have also been given to profoundly deaf people who have some residual hearing, but get no benefit from current hearing aids. In most cases of so-called 'nerve deafness' (sensorineural deafness) the nerve of hearing (auditory nerve) is intact, and it is the cochlea which is not functioning. The nerve can be stimulated electrically to give a sensation of hearing and this is what an implant does.

Cochlear Implants and Deaf-Blind People

The reluctance to select those with visual impairment for cochlear implantation relates to the fact that until recently the implant had been seen as an aid to lip reading only. Even the identification of environmental sounds, which would be very valuable to a deaf-blind person, has to be learned, and is probably difficult to do without vision.

However, the development of multi-channel devices, particularly by the Nucleus Company in Australia, has resulted in a growing number of patients with implants who can distinguish speech without lip reading. Some are even able to use the telephone normally. These patients are still in a minority among implant users, but it does show the way for the use of this technique for the deaf-blind.

One of the difficulties is cost. The Nucleus device costs £11,000 against the UCH/RNID device of £1,200. At present the UCH/RNID cochlear implant programme is the only one in the UK to

be regularly implanting patients, but we are only using single channel devices at present. In future we are sure that we will be using multi-channel devices but this will depend upon their reliability and their cost.

Our philosophy is that where totally deaf people can benefit from the psychological advantages of returning to a world where there is sound (albeit not very normal sound) the deaf-blind person could be helped immeasurably more in view of the dual handicap. Our team is heavily committed with the current programme of single channel cochlear implants for the totally deaf, normally sighted people, but we certainly intend to extend this technique to those who are deaf-blind in the future.

Source: Extracts from a paper given by Jonathan Hazell (Consultant, Neuro-Audiologist, RNIB) at the First National United Kingdom Convention for the Deaf-Blind, August 1987.

The International Newsletter for the Deaf-Blind.

Malta

It seems that there was an epidemic of rubella on the small Mediterranean island of Malta about four years ago. We hear of several three-year-old deaf-blind children there. The Maltese authorities are making contacts with other countries, and hope to develop something for these children.

New Law Passed

A law on Education of the Deaf was passed by the Congress of the United States.

This law created a 12-member Commission on Education of the Deaf. The law also changes the name of Gallaudet College to Gallaudet University and authorises an endowment for the Gallaudet University and National Technical Institute for the Deaf.

Deaf-Blind American

Access to information is often denied the deaf-blind person for a variety of reasons: 'They wouldn't be interested', 'He doesn't have the background necessary to understand that', 'She would only want to go and we don't have the staff' or 'I know he/she is incapable of ...'. These are some of the oft repeated reasons that are given for denial of information. It is interesting that these are exactly the same kind of reasons that were given to justify not involving parents in providing programmes for their deaf-blind children twenty years ago.

The deaf-blind should have access to appropriate information about age and developmental functioning, and a conscious and planned approach must provide for exposure to an ever widening range of information. Newspapers, local radio and television programmes, public bulletin boards all provide excellent sources for finding out such information.

Information and Decision Taking

Most deaf-blind individuals do not have the ability to access such information directly and therefore they should receive help to do so. The first step in the process is to draw their attention to such information in a meaningful way. Information about an activity that they enjoy is a good starting point but unless the information is connected to the activity in a way that makes some sense, little will be accomplished except to prove that the concept will not work.

Initially the information should result in the participation in an activity that the deaf-blind person enjoys and the information must provide the basis for decision making. At a simple level, the decision as to whether to go and get more milk is dependent on knowing how much milk is in your glass, where the milk is kept and if getting more milk is permissible. At a higher level of functioning it may involve budget, shopping lists, transportation problems and a host of other considerations.

If you or I do not have the opportunity to make decisions based upon this type of information, because someone else plans when, how, where and why we go the store, we can still learn by just 'going along' or by putting together the information that we obtain from watching and listening to what others are planning to do. We can attempt to do it on our own with a reasonable expectation of success. The deaf-blind individual does not

have that option.

Providing information to the deaf-blind without giving them the opportunity to make decisions which affect their lives in a meaningful way will not promote integration. If a programme is to foster the skills needed for true integration it must provide constant and ongoing opportunities to utilise information to make decisions which will affect their life in a meaningful way. Such decisions may be as simple as deciding whether to drink milk or pop or as complex as choosing which job you wish to do.

Decision-making is a skill which must be taught just like any other skill. The acquisition of the skill starts with making choices about simple but meaningful things concerning everyday routines. An advantage with this approach is that it also promotes dialogue that is so necessary for the meaningful acquisition of language.

The decision making process must be expanded to involve all

aspects of living. Recreation activities must provide for alternative choices and one of the choices available in every area must be the ability to say 'No, I don't want to do the activity now'.

The integrated deaf-blind person must have the same type of age/functional appropriate choices as his non handicapped peers. Decisions are the engine of our life. They provide us with the means of control over our environment so necessary for good mental health. We often hear of the problems presented by the deaf-blind young people when they reach their later teenage years. It has been our experience, when there is no medical reason for such behaviour, that it often occurs when the congenital deaf-blind young person has desires that he or she does not have the language necessary to express, or when he or she is being required to do something that they do not want

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France

1987 was a very busy year for us in France because we were preparing the 9th International Conference held in Poitiers at the end of July. I have to thank all the people who made that event exciting and useful: the planning committee and particularly the Chairman, Mr John McInnes, who supported us throughout, the French executives Mr William Green and Mrs Dominique Spriet, who were in charge of co-ordination between the French committee and the speakers or members of the planning committee, all members of the French committee; Mr Faivre, for looking after the parents, Mr Berthome in charge of the financial aspects, Mr Gimenez for taking care of everybody (reception, bar, tours, international party), Mrs Jean who organised the interpreters and translators, and all the people who worked to make it a good Conference (reception, computer, transportation, video devices, sound systems etc.)!!

On behalf of the French professionals and parents, I want to say that the Conference was a unique opportunity to meet other professionals and parents and to share experience, theory and practice. Local and national authorities who participated – even for a few hours – in the Conference, really felt how professionals working with deaf-blind children were motivated and saw how competent they are. It will be easier for us now to initiate new things for the deaf-blind in France.

New Developments

■ The National Association for the Deaf-Blind (ANPSA – host agency of the Conference), had its annual meeting in October and made a general survey of the services now available for deaf-blind adults. One of the main concerns of our association is to meet the needs of all the adults coming from schools or adventitiously deaf and blind.

■ The European Usher Syndrome Study Group will have its next meeting on 14 and 15 May in Toulouse. That meeting will be followed by a 5 day course about Usher Syndrome for French professionals.

■ A new programme for deaf children with additional handicaps (like low vision) is now running in Paris, under the supervision of Dr Dumoulin and with the collaboration of Dominique Spriet.

■ The French committee is still working on the proceedings of the conference. We hope that they will soon be available in English and in French.

Jacques Souriau

An Integration Report Card

Location

(Where he or she resides)

1.0 The setting in which the deaf-blind person resides provides:

	Fully	Some Restrictions	Many Restrictions	Not Applicable
1.1 Private space that is recognised and respected by all other adults and is only entered by others with permission.				
1.2 Free access to his or her private space at times of his or her own choosing.				
1.3 The opportunity to furnish personal living space with furnishings of his or her own choosing.				
1.4 The freedom to decorate living space and arrange furniture if and when he or she chooses.				
1.5 The support necessary to fully utilise all the advantages of the setting in which he or she lives.				
1.6 The support necessary to fully utilise all the advantages that the community has to offer.				
1.7 The freedom to choose with whom he or she will share accommodation.				
1.8 The freedom to change the type and/or location of living accommodation without suffering a significant reduction in the level of support available.				

Programme Environment

2.0 The environment in which formal programming or support services are utilised by the deaf-blind person provides:

	Fully	Some Restrictions	Many Restrictions	Not Applicable
2.1 For the deaf-blind person's unique learning style.				
2.2 A reactive environment that stresses:				
2.2.1 <i>Dialogue.</i>				
2.2.2 <i>Making choices.</i>				
2.2.3 <i>Solving problems.</i>				
2.2.4 <i>Interaction with peers.</i>				
2.3 For a carefully identified and expanding set of alternative choices in the areas of:				
2.3.1 <i>Life skills development.</i>				
2.3.3 <i>Formal and informal education.</i>				
2.3.3 <i>Leisure activities and interests.</i>				
2.3.4 <i>Recreational activities.</i>				
2.3.5 <i>Social activities.</i>				
2.4 For a continuing opportunity to apply maintenance skills at an increasing level of competence in areas such as:				
2.4.1 <i>The choice, purchase, care and repair of clothing.</i>				
2.4.2 <i>The planning, purchase, preparation and serving of food.</i>				
2.4.3 <i>The care, organisation and decoration of personal living space and shared space.</i>				
2.4.4 <i>Budgeting and banking.</i>				

Personal Dignity

3.0 The underlying goal behind all support and programming is to ensure that the deaf-blind person, regardless of age or present level of functioning:	Fully	Some Restrictions	Many Restrictions	Not Applicable
3.1 Receives sufficient undistorted information to make the decisions appropriate to his or her age and level of functioning.				
3.2 Is constantly encouraged to make decisions and exercise control over his or her life.				
3.3 Receives sufficient support to be able to carry out actions which flow from the decisions which he or she has made.				
3.4 Receives sufficient information and support that he or she is able to review the results of their actions.				
3.5 Is able to choose <i>who</i> he or she will interact with and/or receive support from during:				
3.5.1 <i>Vocational activities (to the extent that a non handicapped person doing relatively the same work can choose).</i>				
3.5.2 <i>Recreational activities.</i>				
3.5.3 <i>Leisure activities.</i>				
3.5.4 <i>Social activities.</i>				
3.5.5 <i>Maintenance activities.</i>				
3.6 Is able to choose <i>when</i> he or she will participate in:				
3.6.1 <i>Recreational programmes (such as bowling or horseback riding, crafts, etc.).</i>				

	Fully	Some Restrictions	Many Restrictions	Not Applicable
3.6.2 <i>Leisure time activities (such as shopping, having hair done, attending shows, community events, etc.).</i>				
3.6.3 <i>Maintenance activities (such as cleaning up personal living space, doing laundry, taking care of personal hygiene, etc.).</i>				
3.7 Is able to choose <i>whether</i> he or she will participate in or continue, a specific:				
3.7.1 <i>Vocational activity.</i>				
3.7.2 <i>Recreational programme.</i>				
3.7.3 <i>Leisure activity.</i>				
3.7.4 <i>Maintenance activity.</i>				
3.8 Can change his or her mind about decisions which have been made without any additional penalty than that which would be experienced by a non handicapped person who made the same type of decision.				
3.9 Receives sufficient support, and sufficient time is taken to ensure, that the deaf-blind person fully understands the consequences of his or her decisions including the effect that their decisions have had on others.				

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to do but do not have the language to present a rational argument to get their own way.

Information must be presented in a meaningful way that will encourage decision-making about vocational and educational plans, recreational and maintenance activities, and participation in specific activities. If integration is to be successful such decisions must be more than surface gestures. The congenital deaf-blind must have the opportunity to decide what they want to do, when they want to do it, how well they want to do it in order to feel satisfied with their efforts and above all *with whom* they wish to pursue the activity. They must have the freedom to experiment, choose to do an activity and then change their mind.

Support necessary

There is a third aspect to this concept of integration. Sufficient undistorted information to make decisions, and the opportunity and skill to do so, means very little unless the deaf-blind person has appropriate support which will enable him or her to turn decisions into actions.

Many of you are no doubt aware that The Canadian Deaf-Blind and Rubella Association co-sponsored a study on the needs of the deaf-blind in Canada. The report that resulted from the study was entitled *Intervention Is The Key* and focussed on the needs of the deaf-blind as expressed by deaf-blind. The primary need identified was that of appropriate intervention which would foster true integration. The persons who will supply this support were called intervenors, and the intervenor is defined as a person who supplies sufficient undistorted information to allow the deaf-blind person to make decisions and sufficient support to permit the deaf-blind to carry out those decisions successfully.

DEFINITION: *A deaf-blind individual can be said to be integrated when he or she lives in a setting which provides compensation for the handicaps associated with multi-sensory deprivation, an opportunity to control his or her life through unlimited access to information upon which to base personal decisions, sufficient support to carry out those decisions and the right to choose with whom he or she will associate within the same limits that are enjoyed by the non handicapped population.*

Integration, as has been stated

previously, is something the congenital deaf-blind person will *do*, and is not something that will be done to a work place, living accommodation, or leisure activity. The deaf-blind person will have an integrated lifestyle. However, if he or she is to enjoy such a lifestyle he or she must have the skills necessary to do it.

All such skills must be taught and then integrated into the daily routines of living. Both receptive and expressive communication must be encouraged. Just teaching language will not be enough. As Father van Uden and Dr Jan van Dyjk so often point out in their writings, dialogue is essential if expressive communication is to be encouraged. Without the skill to use expressive communication both appropriately and effectively the possibility of integration into society is severely limited if not prevented altogether.

If integration is to be fostered life skills must be much more than 'living skills' as conceived by those who work with the retarded. The carefully developed scales and approaches used with the mentally retarded may be used as a starting place if you wish, but they must not become lists which will limit growth and define experiences and long term goals. We must always bear in mind that one of the premises underlying the preparation of such lists is that when the retarded person reaches the limits imposed by the list they will have the foundation that will allow them to continue to develop their skills through spontaneous, incidental and/or planned interaction with the environment eventually to reach their maximum potential. They receive the contextual, visual and auditory cues necessary to foster transfer and modification that are so often denied or distorted for the deaf-blind.

Transition

We are all aware of the need to teach vocational skills. Indeed, the new catchword on our side of the Atlantic is 'Transition'. There is no doubt that prevocational and vocational skills must be introduced and taught in a specialised manner to the deaf-blind. However, what must not be forgotten is that there are more handicapped individuals who do not succeed in vocational placements because they fail 'coffee break' than those who are released because they lack traditional job skills. With the new and ever more advanced technical support available more and more vocational opportunities are opening to both

the adventitious and congenital deaf-blind, but electronics cannot and will not take the place of the social skills necessary to become integrated. These must be taught because they will not be learned through secondary and tertiary exposure prior to, or while in, the work placement.

Vocational, life, communication and social skills are essential if the deaf-blind are to become integrated. It is equally important that the deaf-blind person has good recreation and leisure activity skills and the support necessary to employ them when and where they choose.

If the deaf-blind individual is to succeed he or she must also have a positive self image. They must view themselves as worthwhile, successful individuals with whom people will want to interact. This will not be accomplished in a day. The foundations will be laid in mother's arms and another brick will be added every time the deaf-blind infant, child or adult interacts meaningfully with the world.

Finally, the deaf-blind must be taught to *enjoy* life. They must be surrounded by people who enjoy interacting with them, people that enjoy life themselves, and above all, people who will make sure that the deaf-blind person understands and enjoys what he or she is doing because he or she has sufficient undistorted information to know that the attempt has been successful. Without this attitude all of the government programmes, private support, and careful skill development, integration will not take place. Integration is a state of mind that we can foster but we cannot make happen.

In 1980 I had the opportunity to present a paper at the IAEDB conference in Hanover based on a survey of parents and professionals who worked with the deaf-blind. At the conclusion of the report one of the conference participants stated that 'These people want too much! They should be satisfied with what they had'. It is quite evident that in many countries neither parents or professionals were satisfied. United by common concerns they are taking an active and often a leading part in the improvement of programmes and the delivery of services. Deaf-blind people, particularly congenital deaf-blind, are receiving programmes designed specifically to meet their unique needs. It is our hope that this paper will spark some debate and play some small part in the developing of effective integration strategies to meet individual needs, and eventually result in a criteria against which existing and new programmes may be judged. ■

European Usher Syndrome Study Group Meeting

This, our third meeting in Europe to study Usher Syndrome, was organised by Patrizia Ceccarani, between May 1 and 4 in Osimo, Italy.

The principal of the Lego del Filo D'Oro, Luigi Giacco, welcomed us warmly on the first day with the hope that our presence would influence awareness for Usher Syndrome in Italy where it is still largely unrecognised.

State Awareness in Europe

Seven European countries were represented this year. William Green reported that in France interest in Usher Syndrome had improved since 1985 and that now they were looking forward to a National Awareness Week in 1988 in Toulouse. Through their efforts, Usher Syndrome is now an element in the training of teachers of the deaf in France.

From Hanover, Dietrich Bunck reported that his centre for deaf-blind people was beginning to be recognised as a place where people with Usher Syndrome could come for advice, training and short rehabilitation courses. Salvatore Lagati from Trento reported that few people were known to have Usher Syndrome in Italy.

Of all the European Countries the Nordic Countries are by far the most advanced in their awareness and services for people with Usher Syndrome. This was demonstrated by the reports from Christer Degsell, Birgit Friele and Jes Kryger.

From Orebro in Sweden Christer reported on the consideration that is given to lighting for pupils with Usher Syndrome. Birgit Friele, a member of the Central Team for Deaf-Blind services reported that they were aiming to diagnose and counsel much earlier in Norway to prevent secondary problems happening as a result of ignorance and neglect. Jes Kryger, told us about the

systematic studies being conducted throughout the five Nordic countries to find out the numbers of deaf-blind people. Overall today there are 3,000 deaf-blind people in all the Nordic countries and of these 30% are congenitally deaf. In Denmark an RP (retinitis pigmentosa) register has been opened to study the condition and in one country it has been agreed to examine the retinas of all people who report a mild hearing loss.

Conclusions

For me this meeting threw up many questions both for Usher Syndrome and for the future of the EUSSG.

On Usher Syndrome itself it became apparent through our discussions that more thought needs to be given to defining the various types of Usher Syndrome. Much harm can come if Usher Syndrome is wrongly diagnosed or diagnosed very late.

As to the future of the EUSSG it was recognised that for it to continue to be active, each country represented needs to contribute some study or case work which can be shared by all. Before the next meeting there would be a call for papers and the contact person in the EUSSG could invite people with specific knowledge to present papers.

We also recognised that we would need some funds from the EEC to help with the cost of translation.

Finally, we accepted the kind invitation of William Green to meet in 1988 in Toulouse and to take part in the first day of their National Awareness Week for Usher Syndrome for the whole of France.

1988

The next meeting at Toulouse, France will be from 13-15 May 1988.

Members of EUSSG have also been invited to present papers at the first day of the Usher Syndrome National Awareness meeting in France.

Mary Guest

Canada including three to five day 'hands on' workshops and two week courses leading to proficiency certificates as intervenors or trainers of intervenors.

The Canadian National Institute for the Blind and the Deaf-Blind Helpers League are to establish a residential home in Toronto for older adventitiously deaf-blind people.

The Canadian Deaf-Blind and Rubella Association, in collaboration with five Canadian provincial governments, are establishing five training programmes, each with some residential accommodation, for young congenitally deaf-blind and early adventitiously deaf-blind young people.

A Lifetime's Work Honoured

Miss JOAN SHIELDS (UK) was awarded the first ever Distinguished Service Award of the IAEDB at the Poitiers Conference in July 1987. Joan had given 42 years of service as a teacher, to blind, deaf and deaf-blind children, working chiefly for the RNIB. She was the first teacher, appointed in 1952, at Conover Hall School's deaf-blind unit (now called Pathways) after special training at PERKINS. Starting with two deaf-blind children she had 30 resident students when she left in 1976.

She then ran the RNIB's advisory service, initially for pre-school children, but spreading to older age groups.

We wish Joan a happy and fulfilling retirement.

United Kingdom



England

The Government's Department of Education and Science has been carrying out a survey into the number of deaf-blind children in schools around the country. It hopes to publish the results, with proposals as to how these children's educational needs should be met, quite soon.

A one-year course for teachers of deaf-blind children will start in October 1988 at Birmingham University.

Scotland

Overbridge, the Further Education Centre for deaf-blind young adults, is opening its second Family Unit in March 1988. The new unit will provide for six students, bringing the total number to 12.

Overbridge is a large converted house in the suburbs of Glasgow. Here, students can learn basic communication and self-help skills, and follow individual programmes aimed at realising their potential. The Centre is forging links with local services, so that the students can benefit from meeting sighted hearing people.



Canada

The Canadian Deaf-Blind and Rubella Association has established a range of training courses to be held across

Linda and Malin – Two Deaf-Blind Children in an Ordinary School

Not all handicapped children have to go to special schools. The two deaf-blind sisters Linda, 12 and Malin Eriksson, 9 in Klippan in the south of Sweden are an example of this. They go to an ordinary school together with sighted and hearing children, and they do excellently with the help of special teachers Johan Emericson and Gunilla Brandmark-Jansson.

Linda and Malin have the same lessons as their classmates, but the teaching is done differently. They are taught by their special teachers in the same classroom at the same time, while the class teacher takes care of the other children. They do the same amount of work, and at the exams they are at the same level as the other children.

Both special teachers have a special training for working with deaf and with blind children.

Linda and Malin use tactile sign language. They have technical aids to help them: Brailler, closed circuit TV monitor, a special reading table. Linda also has a computer (a Versa-Braille II) which she handles very cleverly. All their books are in Braille, although they can both read enlarged print.

The two sisters have a great advantage compared to other deaf-blind children, having been born with sight and hearing. They both have good language and can talk to their pals.

But why are they in an ordinary school? Would they not be better off in a special school together with other deaf-blind children? The answer is, there is no such school. There are schools for the deaf, but Linda and Malin still would need the same technical aids and the same assistance as in this school, and here they do not have to leave home.

The two teachers agree that the municipal authorities are very good about the teaching of Linda and Malin. They have been able to attend the courses they need, and they get all the technical aids that they need. This shows in the results of the girls – they are at least as

good, sometimes better, than the other children.

But what about the classmates? Do they help Linda and Malin?

All of them know a little sign language. Linda says it is all right. They sign to me so that I understand and I play with them. Gunilla thinks that there are sighted and hearing children who are more outsiders than Linda and Malin.

In her spare time, Linda dances and rides horses, and writes letters to her 20 penpals.

From *The International Newsletter of the Deaf-Blind*, Vol. 4 No. 3.

Training Course in Ireland

UVOH* and Mobility International will jointly organise a week long project for blind-deaf people in Ireland in the summer of 1988. Experts in the field from throughout Europe will work on the project with the young people and care staff.

While the programme is not yet finalised it is likely to cover such areas as Communication Skills; Social Skills; Training; Language Development; Physical Exercises and Games; and Vibration Techniques.

The project will be partly funded by the Bureau for Action in Favour of Disabled Persons in Brussels.

**(Irish) Union of Voluntary Organisations for the Handicapped, 29 Eaton Square, Monkstown, Co. Dublin, Eire.*

The Irish Adventure

This is the name of an international holiday based in Dublin, Ireland, between 11 and 18 June. Two young deaf-blind women, Anne Murphy and Doreen Heath from the Republic and Northern Ireland, have organised it with help from Mobility International.

It is expected that up to thirty-four deaf-blind people between 18 and 30 years and their helpers will take part. Groups from six or seven European countries are expected to join in.

The very full programme includes visits to the residence

of the President of Ireland and a reception at City Hall, Belfast. For recreation there will be swimming, skating and pin-bowling, special trips to famous beauty spots, a brewery and the Zoo. The group will meet deaf club members and take part in traditional Irish song and dance entertainment.

Would-be participants from continental European countries only should contact Mobility International, 228 Borough High Street, London SE1 1JX. UK. Tel: 01-403 5688, as soon as possible, quoting reference EC-2-88.

Visitors from Kenya

Mr Joseph Tutoek, Headmaster of the Kabernet School for Deaf and Blind children in Kenya, and Miss Alice Kirui, a teacher of the blind from the same school, visited England in November 1987.

Their three-week study tour included placements at the Royal School for Deaf Children, Margate, and Rebecca Goodman Centre, Whitefield School, London, and 'Pathways' Deaf-Blind Unit, Conover.

Dr. Robert J. Smithdas

Dr. Robert J. Smithdas, Litt.d., LHD, has been appointed Assistant Director, Helen Keller National Centre.

Dr. Smithdas, a native of Pittsburgh, Pennsylvania, lost his vision and hearing at the age of four. He attended Western Pennsylvania School for the Blind and Perkins School for the Blind, and in 1945 enrolled in the rehabilitation programme of the IHB. A fellowship enabled him to attend St. John's University.

Three years after receiving his BA cum laude Dr. Smithdas became the first person who was deaf-blind to earn a Master's Degree (in vocational guidance and rehabilitation from NYU). He holds three honorary degrees.

Dr. Smithdas is the recipient of numerous awards. He serves as Chairman of the Committee on Activities of Deaf-Blind People, World Blind Union; Vice President, American Association of the Deaf-Blind; and member of the President's Committee on Employment of the Handicapped, among others.

In addition to his autobiography, Dr. Smithdas is the author of two collections of poetry; several papers; and editor of a National magazine, 'Nat-Cent News', published by HKNC.

In his new position, Dr. Smithdas will be responsible for client advocacy, in-service training, and community education.

He and his wife, Michelle, an assistant instructress in the Communications Department, HKNC, who is also deaf-blind, live in their own home in Port Washington, New York.

International Newsletter of the Deaf-Blind

About Books

A book on the specialised programming for students isolated by sensory impairments, published by Paul H. Brookes, price £23.95 (plus £1.50 post and package) is now available in the UK. It is based on research carried out in America and is called *Innovative Program Design for Individuals with Dual Sensory Impairments*. It is edited by Lori Goetz, Doug Guess and Kathleen Stremel-Campbell.

Aimed at teachers who want to apply the right approach or strategy in aiding the student with minimal sight and hearing, the book gives practical guidance in areas of non-verbal and non-symbolic communicating systems, assessment of residual sight and hearing, orientation and mobility skills, functional living skills and the use of natural cues and prompting sequences. This guide offers clear and specific information on validated teaching procedures.

Over the past 10 years there have been major strides in philosophy and educational techniques for teaching both these students with severe disabilities and those with multi sensory impairments. The merging of these disciplines to benefit children and students is explained in this book while allowing that there is still much to be done – available from:

Quest Meridian Ltd.
145A Croydon Road
Beckenham
Kent BR3 3BR
England

Netherlands

New developments at Sint-Michielsgestel: a centre for visual assessment and guidance

The deaf-blind unit 'Rafael' is a section of the Institute for the Deaf at Sint-Michielsgestel (The Netherlands) which cares for 53 children. It is the only school for the deaf-blind in the country. There is a unit for low functioning deaf-blind children at 'Bartimeushage' in Zeist and hostel for adult deaf-blind, 'Kalorama' at Nijmegen. In a small country with an efficient health and education organization a concentration of care is a positive thing. In all areas there is sufficient know-how and provision to meet the basic needs of deaf-blind persons in the country. The Dutch Foundation for the Deaf-Blind organizes conferences and seminars to create public awareness of the problems of deaf-blind persons.

On the surface the service provided for this group of underprivileged looks sufficient. However, during the years we have received quite a number of requests from deaf-blind persons who were not properly served.

A group which definitely needed attention are the people with Usher Syndrome. Many had lived rather a full life, until the sight deterioration worsened to a degree that they could no longer function adequately at work or within their family. In some instances training at a rehabilitation centre was the appropriate answer; in many cases they were not psychologically ready to become involved in a 6 - 9 months training programme, often far away from home. These persons, although always known to the after-care service of the Institutes for the deaf in the country,



were often very ill-informed about the true nature of their eye disease and lacked the basic knowledge about aids and mobility skills which could improve the quality of their life.

Another group of hearing- and visually impaired children was brought to our attention, children who were placed at schools for the hard of hearing, functioned rather well, but sometime suffered from misunderstanding of the environment in which they lived. Teachers did not know why the child was behaving in a rather unpredictable manner. The same problem faced visually and hearing impaired persons who were placed in residential places for mentally retarded people.

In order to meet the requests of the caring organizations for proper medical, psychological and educational assessment, the Institute at Sint-Michielsgestel decided to establish, as a part of the deaf-blind section, a diagnostic and advisory centre in the grounds of the Institute. Not only clients referred to the centre from outside agencies can be seen by the diagnostic team, but also deaf-blind children from the Institute itself. For special problems concerning their

vision and/or visual functioning the expertise of the diagnostic team can be used: while the Institute's medical department is responsible for regular ophthalmological services. Two experienced eye specialists check the children's vision regularly, prescribe glasses or refer to other specialists if refined techniques are needed in order to gain more special information on the child's eye condition.

When a child is referred to the centre, it will be seen by a team of people who are not only experts in their field of study, but who are able to communicate with children or adults of all developmental levels. In order to gain real insight into the problems of a person suffering from dual sensory handicap, the ability to understand their problems is crucial. The approach of the team is very practical. The actions to be taken are always guided by the questions of the client. If a child is not willing to wear his glasses, the investigations are centred around this particular problem. If another child is unable to perceive the subtitles on the television, the team concentrates on that problem. Giving practical solutions established confidence in the professionals dealing with them. Gradually the 'real' problem shows up. The child who throws away the glasses wants more attention; the person who despises his television set shows his anger at going blind. A multi-disciplinary team can face all these kinds of problems. We work now with an ophthalmologist, two orientation and mobility instructors, a clinical psychologist, an audiologist and a co-ordinator who has a basic knowledge of all these disciplines.

It is our policy to include spouse, friends, parents and teacher in the assessment and discussion of the results. If the client is literate we write a report which he can understand. If special training is recommended, e.g. mobility or working with low vision aids or computer, this can be provided at the Institute on a day or short-stay basis.

After one year of work with a very enthusiastic team I can confidently say that what a deaf-blind person really needs is not technical aids in the first place, but people who share and care, who listen with their full hearts to the client's problems. A most rewarding job!

Dr J.P.M. van Dijk
Co-ordinator Visual
Assessment Centre

Untranslated Texts Available

We have Russian language texts available of the following articles from the *Journal Defectologia*, the organ of the Pedagogical Academy of the USSR.

1. EEG Study of Deaf-Blind Children by M.N. Fishman.
2. Development of braille sign image with special means in deaf-blind children having residual vision by G.N. Bepalov

3. Conditions of the formation of the initial image in deaf-blind children by T.A. Basilova
4. Drawing activity of a deaf-blind child acquiring verbal speech by E.L. Goncharova
5. Twins and the phenomenon of deaf-blindness by G.P. Bertyn

Photocopies of these articles will be supplied if requested from the Assistant Editor.

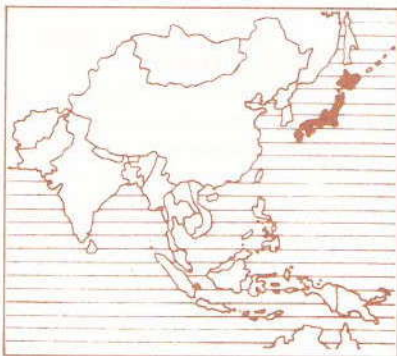
International Conference at Poitiers

The International Association for the Education of the Deaf-Blind (IAEDB) this year celebrated its 25th anniversary when it held its 9th World Conference at Poitiers in France from 26 July to 1 August. The Association was formed at the first conference held at Condoover Hall School in 1962. This year some 450 teachers, family members, classroom assistants, care assistants, residential social workers, voluntary organisation representatives and deaf-blind people themselves from 27 different countries made this conference the largest and most diverse of all.

A number of notable events must be reported. The largest-ever number of parents – 63 altogether – were present and during the Parents' Session, the meeting was addressed by the French Secretary of State for Social Security.

The Conference saw a small rebellion by the brothers and sisters of deaf-blind children whose resolution to have the term 'parents' replaced by 'families' when referring to matters affecting the whole family, was unanimously approved.

The Conference was organised on a plenary session/workshops



Japan

Mrs Sadoko Imamura reports that there are no statistics available on the population of deaf-blind. The number of children who have been found has been relatively low (no numbers available). School age deaf-blind children in Japan usually attend either schools for the deaf or blind but no formal unit has been established.

basis and the themes for each group were:

- Educational Assessment
- Integration
- Educational Programming
- Towards Independence for Lower Functioning Young Adults.

Awards

The Conference was particularly marked by five awards. Perkins School for the Blind in Massachusetts regularly presents Anne Sullivan* awards to deserving people active in the field of deaf-blind education. This year four such

awards were made by Mr Kevin Lessard, Head of Perkins. They went to:

- Lieke de Leuw (Netherlands)
- John McInnes (Canada)
- Patty Taylor (USA)
- Paulette Degorce (France)

At this Conference, the first IAEDB Distinguished Service Award was made to Joan Shields of Condoover and the RNIB for her 42 years of service in the education of deaf-blind children, 1942-87. See page 22.

**Anne Sullivan was Helen Keller's teacher, companion and amanuensis.*

The Philippines

The Deaf Evangelistic Alliance Foundation Inc (Laguna Christian College for the Deaf) wishes to thank most sincerely all organisations which have sent literature to help further its work with deaf-blind multi-handicapped children in the Philippines.

The number of pupils is four, the most recent newcomer being an eight-and-a-half year old congenitally deaf-blind girl, the only daughter of deaf parents. She is considered to be a low-functioning deaf-blind child, slightly mentally retarded and, since she has had no formal schooling until now, has no definite language.

A 14 year old girl, who came to the school in July 1986 with almost the same problems, unable to communicate or even to perform the very basic functions of daily living, can now mobilize herself independently and do some chores without waiting for orders from her teachers. She is also able to understand some school lessons using imitation and functional signs.

One young man graduated in March 1987 as a first year high school student. The many problems faced by the foundation include the need for assessment materials, printed books on the subject of multi-handicapped children, programme guidelines, and equipment. Both the Head of the Deaf-Blind Department, Mr Jose G. Cuaterno, and his wife, teach children



– all of whom have very differing abilities.

Mr and Mrs Cuaterno, having limited experience in the philosophy teaching of such children, are studying for a degree in psychology. There is no money available for them or for one of their teachers to attend seminars and workshops only available in other countries, although there is a great need for them to be trained in the teaching and guiding of multi-handicapped children.

The school depends upon gifts and donations in its own country and from abroad – the Philippines having no educational and vocational programmes for these kinds of handicaps.

Books, leaflets and other printed materials relating to multi-handicapped children and deaf-blindness are still urgently required and can be sent to Mr Cuaterno at the Deaf Evangelistic Alliance Foundation Inc., School Site, Paowin, Cavinti, Laguna, Philippines 3704.

Beroz N. Vacha

Project Nordic Directory for Staff to Deaf-Blind Services

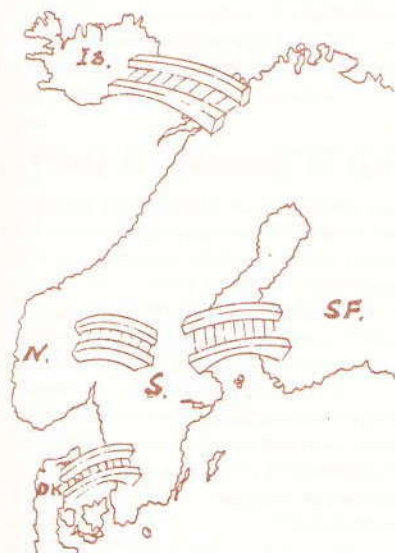
Northern Europe sees a unique example of co-operation between countries. The five Nordic countries—Norway, Sweden, Denmark, Finland and Iceland—have a joint Training Centre for Deaf-Blind Services. Perhaps because of this co-operation the Nordic countries can boast some of the most exciting projects for deaf-blind children and young people in the world.

The Nordic Co-operates

The Nordic countries have a good and long tradition of co-operation in various fields.

Through the Nordic Committee on Disability the Nordic countries co-operate on research related to disabilities; an example is the development, field testing and information on technical aids and devices for handicapped persons.

The Nordic Staff Training Centre for Deaf-Blind Services is another sample of the 'boundless' Nordic. By our joint efforts and knowledge and resources new projects can be worked out.



Project Nordic Directory for Staff to Deaf-Blind Services

The Project Nordic Directory for Staff to Deaf-Blind Services consists of a series of materials for use in

Project Nordic Directory

Project Nordic Directory—a series of materials for use in staff education. The first three books will appear on 1 March 1988:

Directory no 1
Arno, T, Janborg, L H and Thommessen, M: *Feeding Problems in Congenitally Deaf-Blind Children and Youth* (translated from Norwegian)

Directory no 2
Rodbroe, I: *Treatment with Hearing Aids. Maintenance of Hearing Aids* (translated from Danish)

Directory no 3:
Cyrus, M: *Mobility for Deaf-Blind Persons* (translated from Norwegian)

To appear one month later are:

Directory no 4:
Vester, M: *The Physiotherapists' Work with Deaf-Blind Children* (translated from Danish)

Directory no 5:
Eriksen, B: *The Deaf-Blind Child in the Family* (translated from Danish)

Enquiries about the Nordic Directory and these books should be sent to:

Nordic Staff Training Centre for Deaf-Blind Services
Slotsgade 8
DK-9330 Dronninglund
Denmark

staff education both in Nordic and national connections.

Through the years of Nordic co-operation in the Deaf-Blind area consistent requests for materials for staff education have been expressed.

The materials composing the Nordic Directory will cover topics that are relevant to staff working with deaf-blind persons, both congenitally and persons who have become deaf-blind later on.

The Nordic Directory will therefore try to meet the needs for materials for the teams co-operating with the deaf-blind individuals and will cover medical, cultural, pedagogical, social and psychological topics.



A Series of Materials for Staff Education

The materials of the Project Nordic Directory consist of booklets and books combined with video tapes and/or slides.

The material on education in music will consist of a booklet with a video tape.

And a project on environmental factors will be published as a book with slides to go with it.

Documentation and Research

Staff to deaf-blind services in the Nordic countries have through a series of years collected a considerable amount of knowledge.

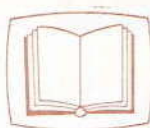
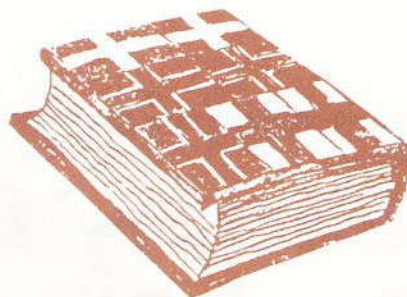
This knowledge can be shared with colleagues through documentation.

In this way the Project Nordic Directory will aim at encouraging and supporting Nordic colleagues to ensure documentation of their work. Through publication others can benefit from their experience.

Due to their documentation and experience Nordic colleagues will be able to express a need for research, either theoretical or empirical. The Project Nordic Directory will for this reason also help in formulating and accomplishing research projects for the benefit of deaf-blind persons.

For the accomplishment of the Project Nordic Directory the Nordic Committee on Disability and the Nordic Staff Training Centre for Deaf-Blind Services have agreed on collaborating with a project coordinator for a period of two years from 1 August 1986 till 1 August 1988.

Through contact with individuals, organisations and institutions working for the deaf-blind population, the project coordinator will motivate and support the elaboration of materials for the Nordic Directory.



Production and Distribution

The materials will be produced at a recently established publishing business and will be distributed through the Nordic Staff Training Centre for Deaf-Blind Services.

The Nordic Newsletter which is issued twice a year will bring news on the materials produced, and will also contain an order form.

Joint Efforts Increase our Competence

The Project Nordic Directory for Staff to Deaf-Blind Services unites the Nordic countries in the task to co-ordinate the efforts of organisations, institutions and individuals as they co-operate on documentation and research and share the outcome for the benefit of deaf-blind persons.

The Nordic Committee on Disability and the Nordic Staff Training Centre for Deaf-Blind Services have initiated this project. The project coordinator will compile the material before its production and distribution.

There is, however, also a strong need for other Nordic organisations and institutions, to support concrete projects. We can then realise the requests expressed at the Nordic Conference for Staff to Deaf-Blind Services in 1985 saying that documentation and research should be encouraged in the years to come.



Singapore

The Singapore School for the Blind set up a unit for deaf-blind children in January 1985. It was strongly supported by four volunteers who saw the necessity for starting a programme for six deaf-blind children. These six children were in the pre-primary school for the deaf, but due to their low vision they were functioning inadequately and therefore asked to leave.

In May 1985 Dr Jean Kenmore and Beroz Vacha were invited to set up the unit, train the volunteers, one teacher and the parents. The training period was of five to six weeks duration; followed by a programme for one year. In July 1986 Beroz Vacha again followed it up with training of two teachers and volunteers. This was intensive training, including demonstrations, lectures, and a one day Open Workshop to which officers and educators from allied fields, the



Ministry of Education and Ministry of Welfare, were invited as observers. The Community Chest of Singapore has assisted the programme financially as well as publicity-wise. Parent-teacher participation is quite an important activity of the programme.

The programme is well on its way. At the moment there are seven deaf-blind (partially sighted, profoundly deaf) children - and one totally deaf-blind girl (23 years old).

Beroz N. Vacha

This is how we'll start

The project co-ordinator will get in touch with Nordic colleagues to reveal and to initiate concrete projects.

But if you or your colleagues have a good idea for a project, you'll find support by contacting:

**Project Co-ordinator
Kurt Vinterhoj
Glentevej 17, Norhalne
DK-9430 Vadum
Denmark**

Phone +45 8 26 88 50

or

**The Nordic Staff Training Centre
for Deaf-Blind Services
Slotsgade 8
DK-9330 Dronninglund
Denmark**

Phone +45 8 84 34 99

About our School

The Helen Keller Institute for the Deaf and Deaf-Blind in Bombay, India, is one of the only established deaf-blind units in Asia. It was established through the determination and strength of Beroz Vacha. She presented this paper about her school at the conference in Poitiers.

This is not a paper propounding any technical information – but a paper on *what do we do!* It was the desire to recognise a place for a multi-handicapped child, especially a deaf-blind child, that gave birth to our Institute. It is a pioneering deaf-blind unit in India and so far the only one of its kind: perhaps it was the first in Asia, excluding Japan. We believe that 'As each star differs in brightness, so do the children of man – yet each serves its purpose under one god and one nation and each is entitled to an opportunity to achieve his fullest potential ... to adjust to his environment ... to grow physically, emotionally, intellectually, socially and spiritually ...'

Further we are also sure that *no* child can do without education, that it is his birthright to have at least the basic education for him to develop and live fully.

Our beginning was very modest – two teachers and myself, three children (two deaf-blind and one deaf) and two small classrooms in one of our teachers' homes with *just* 15 dollars (American) to start with. But our hope was in the educability of our children, faith in ourselves, and above all we knew where we were going!

In India there is a widespread ignorance about the deaf multi-handicapped child. It is more often labelled mentally retarded, because people he comes in contact with know nothing better! This was the situation which stimulated us to start a programme for a deaf-blind child. A challenge unto the society – to the child and to us. Schools for the deaf in India are on a system where they are unable to recognise the needs or to provide a programme for such a child. For this child needs 'a total approach'. It is so sensorily deprived that every available opportunity through different stimulations and communications has to be put into a learning situation.

THE AUTHOR

After training as a teacher in Bombay at the EAR (Education, Audiology and Research) Centre Beroz Vacha won a scholarship to study at Manchester University from



where she emerged as a committed oralist in 1970. However at an International Conference in Stockholm she encountered deaf adults who were signing and she began to realise the importance of manual communication.

On her return to India, Beroz was appointed Principal of the EAR Centre. In 1974 she went to

America, visiting Gallaudet College and schools using both oral and total communication methods. She became a convert to the new philosophy of 'Total Communication'. The EAR Centre was firmly oral in its practices so Beroz resigned and, after a spell as a lecturer at Bombay University, decided to set up her own school using her preferred methods.

She opened in 1977 with three children against enormous odds: no money, no buildings and no support organisation. Eventually her supporters grew and the Helen Keller Institute for the Deaf and Deaf-Blind was founded.

The motivating force which has brought her, her children and staff so far is well reflected in the poem that introduces the school's prospectus:

*wind blew
falling leaves brushed past me.
in a million years I would never have
guessed
that they had sound
that they had colour
if you hadn't told me.*

Started in July 1977 from three children our school population is now 54 children. 14 deaf-blind, three dyspractic and 37 deaf children. We also have a residential unit for the deaf-blind children, who live outside Bombay. Our programme for the deaf-blind child consists of a functional education which allows him to:

- relate to himself;
- relate to his peer group and other members of his close proximity.

Therefore he learns language— manual and very limited oral skills. Mobility skills come from daily activity as do functional independence skills. Because our oldest student is only 16 and because most of them only communicate manually some may learn to read but few to write. We also have music and movement, percussion music, art and craft, and swimming.

For group outings every deaf-blind child has a partner in a deaf

child and for some activities like camping our two older deaf-blind girls have girls from other regular schools.

■ We also have mainstreamed three of our deaf-blind children with the deaf children – this is an experiment we are just trying out.

■ Two boys of low vision and severe profound hearing loss who are now 20 years old are in a sheltered workshop – automobile repairs. We strive to do all things for our children—our goal for them is: a functional child, totally developed within his own framework of abilities.

■ Parent-Teacher partnership: two of our parents are now teachers' aids. Their total involvement has given them courage and freed them from the emotion of total hopelessness. They in turn provide a great emotional support to our new parents and thus the whole programme works in a controlled freedom situation.

■ Home-guided programmes are available to our parents on a once-a-week basis: the teachers who are teaching the children already in the school once a week (every Friday) visit the home and help the child and the parent in home situations – thereby supporting the parent to overcome the problems she faces with the family – through counselling and other guided information.

■ The residential unit for our deaf-blind children from outside Bombay is proving successful. Even here

once a week the child's day teacher goes to the residential unit to see how the child is functioning.

An inservice training programme on an on-going basis is compulsory for all our teachers, teacher aids and care workers. This includes communication skills and child development topics. We are trying to meet as many challenges as confront us, for our deaf-blind programme is financially supported by local donations from various organisations and a part of the staff salary is now funded by the Central Government of India (New Delhi) Ministry of Social Welfare.

I will be failing in my duty if I did not acknowledge the support of foreign organisations – *Nederlandica Caritas, Misereor* (W. Germany), *Royal Commonwealth Societies for the Blind* (UK), *Institute Voor Doven – St. Michielsgestel, Perkins – Boston, HKNC – Long Island, NY, Christoffel Blinden Mission* (W. Germany) who in their own way have recognised our programme and supported us educationally/financially.

The presentation of the 20 minute video film on orientation and mobility shows the range of children from low functioning to high functioning child, in their various activities, and that given an early intensive training a child who was once written off has now a place to stand.

Finally I end my paper acknowledging the strong support for this present organisational

committee who made it possible for me to come and share in the proceedings of the IAEDB Conference at Poitiers, France.

Beroz N. Vacha
Principal
The Helen Keller Institute for the Deaf & Deaf-Blind
Bombay, India.

European Conference on Staff Development in Services to Deaf-Blind People

A European Conference on 'Staff Development in Services to Deaf-Blind People' will take place in Osimo (Ancona) Italy from 20 – 22 November, 1988. This working conference will examine important aspects of training staff to work with deaf-blind children and young adults. It will be of interest to all those involved in providing or organising training, whether in schools, adult centres, associations, colleges, universities, etc.

Background

In 1986, the Nordic Staff Training Centre for Deaf-Blind Services held a exploratory conference to examine the possibility of co-operation throughout Europe on staff training in services for deaf-blind people. As a result of this meeting, it was agreed to hold a second European conference, and a planning committee was appointed by the delegates. This committee investigated options for the conference organisation, and has invited the *Lega Del Filo D'Oro* to host this conference. We are grateful to this organisation for their support.

Programme

The programme will include discussions on the philosophies and ideologies of different training programmes, the structure and content of courses, and teaching materials used and methods of evaluation. Participants will also visit the *Instituto del Fila d'Ora* – the Italian National Institute for Deaf-Blind in Ancona.

Preliminary registration is required by 1 May 1988. For full details, write to:

The Secretariat
European Conference on Staff Development
Lega del Fila d'Oro
Via Montecerno 160027
Osimo
Italy
Tel: (071) 7131202



The Bahamas

The Bahamas Council for the Handicapped is the voluntary, national umbrella organization for the disabled and all organizations and individuals concerned with the disabled in the Bahamas.

The Bahamas Council for the Handicapped recognizes the need for a resource library for the disabled, their families, students and anyone interested. It is therefore in the

process of collecting material and information that will be housed at the Council's centrally located office and open on a daily basis.

I should be most grateful if you could send us:-

- information about your organization, relevant materials, leaflets or publications;
- a list of any materials that you sell so that we could purchase them if needed.

Please either write to us directly at:

Bahamas Council for the Handicapped
P.O. Box N3938
Nassau
Bahamas

Any assistance you can give us would be much appreciated as at present resource information for the disabled is limited and not centralized for easy access.

Wayne Thompson
President

Classic Books on Deaf-Blindness

An occasional series to remind you or introduce you to works fundamental to the understanding of aspects of deaf-blindness.

Until 1941 rubella, so-called 'German Measles', had not been considered to be seriously dangerous. But Gregg (1941) detected a very impairing infection caused by the rubella virus, passing from the pregnant mother to the foetus, even - as became evident later - whether the mother herself had been ill or not.

This study concerns the impairments found in a group of 81 'victims' of the serious prenatal infection - rubella - suffering from a hearing loss (slight to profound loss) considered to be caused by the rubella virus infection. The time of infection was different in these children, as were the gestational age and the birthweight.

The three prenatal variables (i.e., infection time, birthweight and gestational age) should be carefully considered in the assessment of rubella children.

The author has been invited (1973) by the Ministry of Education of the State of Victoria (Australia) to act as an advisor for the education of multiply

Rubella Handicapped Children

The effects of bi-lateral cataract and/or hearing impairment on behaviour and learning

by Jan van Dijk

handicapped children, especially deaf-blind rubella children. This diagnostic and advisory work was extended in 1976, and in 1980 a follow-up study was executed. During these years the material for this study was collected.

The importance of this study stems first of all from the careful description of a group of Victorian hearing-impaired rubella children on a number of behavioural and psychological variables. The results of this have been brought together into a causal structure. It breaks new ground for a better diagnosis and treatment of these children.

Apart from this, the book shows a comprehensive survey of literature and knowledge, about medical data of rubella children, cataracts, cognitive motor development,

assessment of learning ability and about autism.

The general trend of the author's judgement is definitely positive: these children are mainly educable, show realistic pedagogic opportunities. The author not only describes the crippling aspects of the rubella infection, but also the compensatory forces, making these children a strong challenge to their educators.

1982 ISBN 90 265 0432 2

Dfl. 47.50

Modern Approaches to the Diagnosis and Instruction of Multi-Handicapped Children, Vol. 16.

To be ordered from:
Swets Publishing Service
347b Heereweg
2161 CA Lisse, The Netherlands.

In USA and Canada please order from:
C.J. Hogrefe, Inc.
P.O. Box 51
Lewiston, NY 14092, USA.

Correspondence with the USSR

Dr Salvatore Lagati, Director of Servizio Di Consulenza, Italy, recently wrote to Mr Michail Gorbachov on the subject of Retinitis Pigmentosa. Reproduced below is the letter from Dr Lagati and the reply from the Soviet Union.

Dear Mr Gorbachov,

Re: Information on 'Russian Cure' for Retinitis Pigmentosa

I have worked for the education and rehabilitation of deaf children since 1959. In 1979 I founded the Servizio Di Consulenza (Counselling Service) for the parents of deaf children, and from 1977 I have worked for the deaf-blind too.

Some of my deaf pupils are now going blind. The cause of this double handicap is 'Usher Syndrome' i.e. Deafness and Retinitis Pigmentosa.

To 'cure' Retinitis Pigmentosa the parents of my deaf pupils, and thousands of other parents all over the world, travel to Moscow to the Helmholtz Eye Clinic.

There, Professor L.A. Katznelson uses two medicines: ENKAD and TAUFON.

This 'cure' has, for several years, been available only in Moscow. You can imagine, Mr Gorbachev, how much these parents have to spend in travel, board and room to journey from Italy (and other countries) to Moscow.

My questions are:-

1. Is this 'cure', made by Professor Katznelson, valid?
2. If it is valid, why do the Russian authorities not permit all other countries to use it at home?
3. If it is not valid, why do the Russians not stop people from travelling to Moscow for it?

Please help me to give the right answer to the parents of deaf and going-blind people - and to give the right help.

I thank you personally

and on behalf of the many parents who have children with Retinitis Pigmentosa.

Yours sincerely,
Dr Salvatore Lagati, Director, Servizio Di Consulenza, Via Druso 7, 38100, Trento, Italy.

Dear Dr Lagati,

In reply to your letter of 29 January 1987, addressed to Mr Gorbachov, the USSR Ministry of Health states that the preparations 'Taufan' and 'Enkad' are indeed used in USSR - in particular at the Moscow Helmholtz Research Institute of Eye Diseases in the case of Retinitis Pigmentosa and other diseases of the retina. Stabilization of the process of certain forms of pigmental degeneration of the retina, by means of these preparations, is achieved in 30 per cent of the cases. Regrettably, as yet it is not possible to cure this disease by use of these preparations and other methods of treatment.

As for your suggestion to arrange treatment of patients with RP in Italy by

means of the preparations 'Taufan' and 'Enkad', this regrettably, cannot be implemented at present owing to the fact that the industrial output of 'Taufan' commenced only in 1987, with amounts as yet not satisfying the requirements of the population of this country, while industrial production of 'Enkad' has not yet been mastered.

Taking into consideration what has been stated above, and also bearing in mind the human character of medicine and the available means of treatment of degenerative diseases of the retina, the Ministry of Health cannot deny the right of a patient or his relatives to turn to you for help.

Yours sincerely,
E.V. Kosenko, Head of the Office for Foreign Affairs, USSR Ministry of Health, 101431, GSP, Moscow K-51 Rakhmanovskii per d.3. Russia.

Note: The above letters are published with the permission of Dr Salvatore Lagati.

Faculty of Education
Department of Educational
Psychology and Special Education
The University of Birmingham
PO Box 363, Birmingham B15 2TT
England

Education of Children with Multi-Sensory Impairments (Deaf- Blind) One Year B.Phil (Ed) Course

The University of Birmingham, in collaboration with Westhill College, is offering a one-year full-time degree course in the education of children with multi-sensory impairments. The course will commence in October 1988 (subject to approval by Faculty Boards and Senate). **Inquiries are invited now about the course starting in October 1988.**

The course is designed for teachers working with classes of children and in an advisory capacity. In four specialist modules, it covers aspects of diagnosis, assessment, intervention and curriculum in relation to children with multi-sensory impairments, many of whom will have other handicaps. The course includes a programme of visits and assessed teaching placements.

Applicants must be qualified teachers with at least two year's teaching experience. It is expected that many applicants will come from a background in moderate or severe learning difficulties and may be working with PMLD (profound and multiple learning difficulties) children. The course should cover their needs as well as those of teachers working with 'deaf-blind' children.

The course fee is expected to be around £960 for British and EEC nationals, for others it is likely to be about £3,600, excluding costs incurred in the teaching placements. These should not exceed £300. It is anticipated that the course will be recognised by the DES as eligible for funding under national priority area 8; training to meet the special educational needs of pupils who have severe learning difficulties.

For further information about the course and application procedures, please contact Tony Best on 021-414 4834/4798 or write to him at the above address.

Resources

ROYAL NATIONAL INSTITUTE
FOR THE BLIND
338-346 Goswell Road, London
EC1V 7JE

Reference Library
Select Accessions List:
September - October 1987

Special Groups: deaf/deaf-blind

ANDERSON, Linda. Television access for the deaf-blind. *Nat-Cent News*, September 1987, 18 (1), 21-27.

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DANTONA, R. The development and growth of educational services for deaf-blind children in the United States from 1968 to 1978: dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Education in the School of Education, Health, Nursing and Arts Professions, New York University, 1984. Ann Arbor, MI: University Microfilms, 1987. xiii, 145pp.

DELATINER, Barbara. The joy of art found by touch. *Nat-Cent News*, September 1987, 18 (1), 9-19.

GRANT, B., compiler and editor. The quiet ear: deafness in literature: an anthology. London: Andre Deutsch, 1987. iv, 247pp.

GUIDE DOGS FOR THE BLIND ASSOCIATION. Pioneers in a dark and silent world: (Clark Stevens, deaf-blind, and Nelson, his guide dog). *Guide Dogs for the Blind Association Annual Report*, 1986, 14-15.

MORBEY, Gillian and AITKEN, Stuart. Look I'm here: the implications and results of a demographic survey for resource provision: study conducted 1985-86. Glasgow: Sense-in-Scotland, 1987. iii, 49pp.

NORDISK UDDANNELSESCENTER FOR DOVBLINDEPERSONALE. *Bibliotekskatalog* 1985. Dronninglund: NUD, 1986. 150pp. + Tillaeg 24pp.

... Kontaktnet. Dronninglund: NUD, 25 September 1986.

SLATALLA, Michelle. Rubella babies grow up. *Nat-Cent News*, September 1987, 18 (1), 42) 56.

Conferences

Second General Assembly of the World Blind Union 1988. To be held in Madrid, Spain 19 - 24 September.

Contact: ONCE, Calle Jose Ortega y Gasset 18, 28006 Madrid, Spain.

The Second European Conference of Deaf-Blind People will be held in London, England from October 22 - 27 1988.

Organised by the European Committee for Services to the Deaf-Blind.

The aim of this Conference is to discuss the Services to Deaf-Blind People in Europe, with regard to research; communication and interpreting; social and work rehabilitation; travel and international co-operation. It is open to organisations of and for deaf-blind people. Each country may be represented by two deaf-blind participants accompanied by their guide-interpreters and one professional worker from the field of deaf-blindness. Consideration will be given to the attendance of observers. The programme will be finalised at the next meeting of the European Committee in February. For further information: National Deaf-Blind Helpers' League, 18 Rainbow Court, Paston Ridings, Peterborough PE4 6UP, England.

The Next European Conference

At the Poitiers Conference, it was decided by the IAEDB Executive Committee that the International Conference should be held every four years and recommended that regional conferences should be held during the intervening period.

At the last European Conference on the Education and Management of the Deaf-Blind which was held at the Royal Spermalie Institute in Bruges, Belgium in June 1986, Sense offered to hold the next European Conference in the United Kingdom. The possibilities for this were discussed at a consultative meeting of blind, deaf and deaf-blind organisations in the UK on 20 January. At present, Sense is working to mount the conference during late July/early August 1989, but a fixed date and location have still to be decided. Recommendations will be discussed at the next meeting of the IAEDB Executive Committee which will be held in London during 8 - 10 April 1988.

Conference Timetable

Please notify *Deaf-Blind Education* of any conferences that might interest our readership.

1988

7-13 August

Visually Impaired Infants and
Children
Edinburgh, UK
(see page 23)

23-25 September

Sense National Conference
Birmingham, UK

19-24 September

General Assembly of World Blind
Union
Madrid, Spain
(see page 22)

22-27 October

European Conference of Deaf-
Blind People
London, UK
(see page 22)

20-22 November

European Conference on Staff
Development in Services to Deaf-
Blind People
Ancona, Italy
(see page 20)

1989

late July/early August

European Conference on
Education of Deaf-Blind
UK

Book Review

Multiply Handicapped Children,
Rosalind Wyman, Souvenir Press
(Human Horizon Series) 1986. 234
pages, £8.95 Hardback, £6.95
Paperback.

'In the world of the deaf-blind or the multiply handicapped child nothing can be left to chance'. Rosalind Wyman describes in depth why this is so.

She tells of children to whom things have been left to chance with the result that they have withdrawn from an often confusing and threatening world, perhaps exhibiting bizarre behaviour adopted in an effort to give themselves solace. The children mentioned in the title are those with combined hearing and sight loss, with occasional reference to those who have additional handicaps.

The book opens with a chapter devoted to the sensitive and articulate expression of parents' experiences. As well as making a strong plea for early intervention, the book emphasises the need for continual discussion between parents and professionals before they embark on any remedial programme. Each chapter could be read as a separate essay and there is frequent repetition of the author's strongly-held conviction that these are 'whole children', who have certain limitations placed upon them by handicapping conditions.

Rosalind Wyman dispels much of the mystique surrounding communication by her common sense discussion of the various aspects of both verbal and non-verbal communication. There are useful guidelines for example on how, objectively, to observe a child's behaviour. Information is supported by charts, photographs and clear line drawings. Suggestions for equipment and further reading are helpfully broken down and included in short descriptive passages in the final chapter, 'Extending the child's skills'. There are many useful and practical suggestions in the text together with a comprehensive index for future reference. The strength of this eminently readable book lies in the author's single-minded commitment to the deaf-blind or to the multiply-handicapped child. It provides information and encouraging reading for families of the slow-learning child and in particular for those professionals working as part of a multi-disciplinary team. It should be essential reading for all those whose work brings them into frequent contact with multiply handicapped children.

Extracts from the review by
Olive Cohen, ILEA Teacher for the
Visually Handicapped.

Source: The British Journal of
Visual Impairment, Autumn 1986
issue and the International
Newsletter for the Deaf-Blind.
The book is available from Sense,
311 Gray's Inn Road, London
WC1X 8PT.

INTERNATIONAL SYMPOSIUM ON VISUALLY IMPAIRED INFANTS AND YOUNG CHILDREN

Realities and Opportunities

CHILDREN ★ FAMILY ★ COMMUNITY

An International Symposium on Visually Impaired Infants and Young Children: birth to seven, will be held in Edinburgh, Scotland, 7 - 13 August 1988.

The Symposium is open to parents of blind and visually impaired children, educators, physicians, nurses, psychologists, rehabilitation workers, and others interested in the early education and development of visually impaired children, birth to seven. An important focus of the Symposium will be techniques and services for blind and visually impaired children, including the multi-handicapped child, in rural areas and developing countries.

Special help will be provided for visually impaired participants.

To receive information about the Symposium or requirements for submission of abstracts, and to have your name placed on the mailing list, contact:

Eileen Aitken
Scottish Symposium
c/o Royal Blind School
Craigmillar Park
Edinburgh EH16 5NA
Scotland

Donna Heiner
1975 Rutgers Circle
East Lansing, Michigan 48823
USA

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Rossano Bartoli
Lega del Filo D'Oro
Istituto Nostra Casa
v. Montecerno
60027 Osimo, Italy

Andree Gendron
Institut Raymond Dewar
Montreal, 3600 rue Berri
Prov. Quebec H2R 2Y1
Canada

Anke Granel
Taubblindenzentrum
Albert-Schweitzer-Hof 27
D-3000 Hannover 71
West Germany

Dominique Spriet
Centre pour enfants sourds-
plurihandicappes
33 Rue Daviel
75013 Paris, France

Mrs Beroz N. Vacha
Helen Keller Institute for the
Deaf and Blind
c/o Municipal Secondary School
N.M. Joshi Marg - near 'S' bridge
Byculla (West), Bombay 400011
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Sadako Imamura
Yokohama Christian School for the
Blind
181 Takenomaru
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Marta Triay Perrone
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Montevideo, Uruguay

Bernadette Kappen
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Institute for the Deaf
5271 GD St Michielsgestel
Netherlands

Sonia Jarl
Ekeskolan
Orebro, Sweden

Mr Keith Watkins
3 Duff Street
Turramurra
NSW 2074, Australia

World List of Publications

This is the basis of a list of journals we are compiling which, with the help of our correspondents, we will expand (and correct if necessary) to contain all publications which deal wholly or largely with deaf-blindness. Publications listed should be of professional standard. Sample copies will be welcome at our office in London.

Title	Country of Origin	Language of Text	English Digest	Frequency of Publication	Organ of	Address
<i>The Deaf-Blind American</i>	USA	English	N/A	Quarterly	American Association of the Deaf-Blind	AADB, 814 Thayer Avenue, Silver Spring, Maryland 20910, USA
<i>Intervention</i>	Canada	English	N/A	Bi-annually Spring/Fall	Canadian Deaf-Blind & Rubella Association	Intervention, 71 Limberlost Crescent, London, Ontario N66 2E1, Canada
<i>Le Messenger</i>	Switzerland	French	No	Monthly	ASASM - Swiss Association for the Deaf-Blind	ASASM, Ave de Provence 16, 1007 Lausanne, Switzerland
<i>L'Arcobaleno</i>	Italy	Italian	No	3 times per year	ANIGESCP - Italian Deaf-Blind Dual Handicap Association	L'Arcobaleno, ANIGESCP, Via Druso 7, 38100 Trento, Italy
<i>Defektologia</i>	USSR	Russian	Yes	5 times per year	Academy of Pedagogical Science - Research Methods Journal	119834, GSP Moscow G-121, Pogodinskaya Ul. 8, USSR
<i>Bulletin de Liaison de L'ANSPA</i>	France	French	No	Quarterly	National Association for the Deaf-Blind	ANPSA, 37/39 Rue Saint-Sebastian, 75011 Paris, France
<i>The International Newsletter for the Deaf-Blind</i>	UK	English	N/A	3 times per year	World Blind Union	The National Deaf-Blind Helpers League, 18 Rainbow Court, Paston Ridings, Peterborough PE4 6UP, England
<i>NAT-CENT News</i>	USA	English	N/A	3 times per year	Helen Keller National Centre	HKNC, 111 Middleneck Road, Sands Point, NY 11050, USA
<i>Talking Sense</i>	UK	English	N/A	Quarterly	Sense - The National Deaf-Blind and Rubella Association	Sense 311 Gray's Inn Road London WC1X 8PT, UK