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# DEAFBLIND EDUCATION

**Deafblind Education** appears twice yearly, the two editions are dated January-June and July-December.

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

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

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

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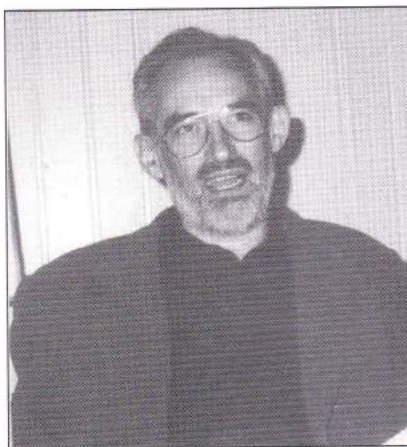
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## CHAIRMAN'S MESSAGE

**A**s you all know the next opportunity for all the members of our association to meet is in Cordoba in July 1995. I very much hope that as many people as possible will be able to attend the Conference, despite the high cost for most of us. The fact that this event is in South America is a great step forward for IAEDB as it presents the opportunity to start promoting awareness and, hopefully, developing services in that part of the world.

At the Conference we will spend some time looking at the future of IAEDB. The growth of the association, together with an increase in international activities undertaken by other organisations make it necessary for us to adapt IAEDB accordingly and make general plans for the future. The Strategic Planning Working Group created at the Executive Meeting in Poland met recently to start discussing



the options for the future and will soon be circulating information as widely as possible. The full strategic planning process is detailed on page 22 of this edition of Deafblind Education.

In general the main discussion points concern the following:

- should IAEDB be a network or a service provider?
- should it cover other aspects of deafblindness in addition to education?
- should we have a professional Secretariat?
- should we develop regional structures?
- what should the overall aims be for the next ten years?

I have to admit that these questions appear to be very distant from the day-to-day work of many of our colleagues. However it is absolutely vital that we discuss them as carefully as possible so as to improve the quality of IAEDB and maintain the opportunity for all members to be active in the association.

**Jacques Souriau**



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# EDITORIAL



**W**elcome to Deafblind Education number 14. I hope there are articles and information here to interest

everyone. We always try to get a balance of reports on countries at different stages in development of deafblind services. In this issue we manage, through reports and articles, to visit all the continents.

We also plan for variety in the articles. There is an article by Hans Borchgrevink based on a presentation he made at the Usher European Study Group meeting in Potsdam. I found this presentation on neuropsychological aspects of communication and development helped me achieve some understanding of brain damage and the effects for some deafblind people so I am very pleased to be able to reprint it here in Deafblind Education. Russ Palmer is a person with Usher syndrome and he and his partner Riitta Lahtinen have written an important article on communication and Usher which includes issues related to relationships or marriage. Our third article features the development of services in India and the enormous challenge being tackled by colleagues there.

As with the last issue we have produced a smaller Spanish edition of some of the content of Deafblind Education. This is being mailed separately to this English edition. Please inform the editorial team if you would like to receive a copy of this.

In the next issue I intend to feature a review of work from around the world on elderly people with acquired deafblindness. We very much need other contributions and indeed comments on Deafblind Education in general.

We have had a very positive feedback to the redesign of the layout and cover of this journal, although some have expressed a desire for further photographs, including one on the cover. We need people to send us photographs to enable this! Deafblind Education will be reviewed at the IAEDB World Conference in Córdoba, so please pass your suggestions to me by that date.

**Malcolm Matthews**



## UNITED STATES



# Perkins National Deaf-Blind Training Project

**In October 1993 the Perkins School for the Blind was awarded a three year national grant to develop a structure to coordinate and utilize the expertise created through national efforts to improve services to deafblind children and youth. This project will work collaboratively to expand knowledge of the educational needs of deafblind infants, children and young adults, and design a model for training which will make this information accessible to professionals and others who are providing a service to this population.**

In order to achieve these goals the project is proceeding through four major phases:

- To develop and convene a national steering committee comprised of leaders from seven university programmes which train teachers of deafblind children, along with national and state providers of technical assistance in deafblindness and consumer and parent organizations.
- To develop teacher competencies in working with infants, children and young adults who are deaf-blind: this will be one of the central activities of the project. The skills will highlight the unique educational needs of children who are deaf-

blind and serve as a guide for the development of pre-service and in-service staff training.

- To organize regional teams throughout the United States to design and implement university based training institutes which will be available to providers of deaf-blind services.
- To develop a model to evaluate teacher competency in providing education for infants children and young adults who are deaf-blind. This goal will ensure that the teacher competencies are truly representative of the educational challenges faced by teachers of children who are deaf-blind.

Six geographically dispersed university sites have been selected as the Regional Centres for the project's training activities. They are:

- Hunter University, NY;
- Texas Tech University, Lubbock, TX;
- University of Washington, WA;
- Florida State University, FL;
- San Diego State University, CA;
- Michigan State University, MI.

The project personnel are employed by the Perkins School for the Blind. They will coordinate all national and regional training activities and oversee the development of teacher competences and teacher evaluation.

**Marianne Riggio**  
Project Director



# DB - LINK

## An American Service from the National Information Clearinghouse on Children who are Deafblind

DB - LINK is a federally funded clearinghouse project with the goal of providing information to parents, teachers, medical personnel and social service providers related to young people who are deafblind (0 - 21 years). It is a consortium project with the Helen Keller National Centre, St Lukes Roosevelt Hospital, the Perkins School for the Blind and the American Federation for the Blind.

The service is available to anyone involved in designing or providing facilities for young deafblind people. It uses resource databases to access a broad spectrum of information on topics ranging from early intervention, health and legal issues, employment and communication needs.

DB - LINK is funded by Services For Children who are Deaf-Blind in the U.S. Department of Education. This aims to assist state educational agencies to ensure:

- the estimated 8,000 young deafblind people aged 0 - 21 receive special education provisions, early intervention and other related services.
- young deafblind people are aware of the programmes, services and support available to facilitate their transition from school to vocations, and to receive assistance for independent living.

If you would like further information on DB - LINK please contact:

Project Director  
DB - LINK  
345 North Monmouth Avenue  
Monmouth  
OR 97361  
U.S.A.

Telephone:

(800) 438 9376 - voice  
(800) 854 7013 - TTY

### DENMARK

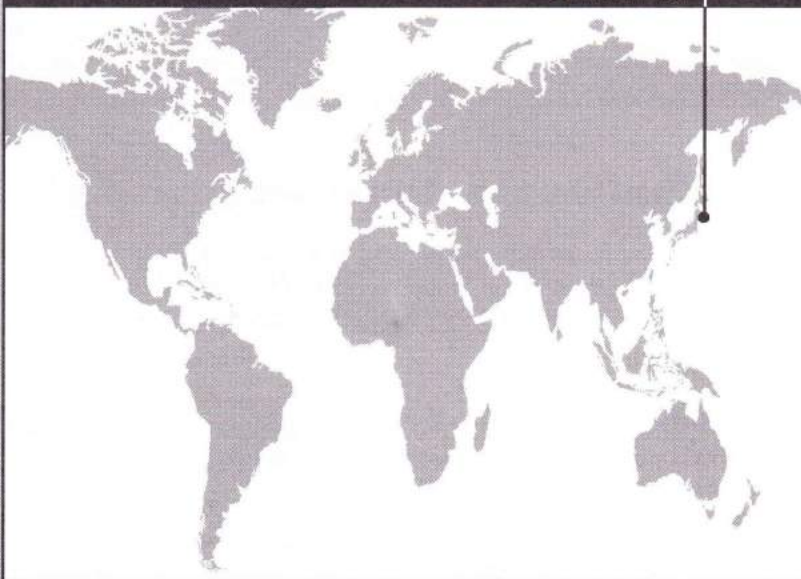


The Danish National Centre of Expertise on Congenital Deafblindness was opened in December 1993 in Hordjylland. This is a three year project to facilitate the development of advisory services and local and national provisions for deafblind people. It forms one part of

an initiative of seven Centres of Expertise for different disabilities.

It is estimated that there are 800 - 1,000 deafblind people in Denmark, of which 200-500 are congenitally deafblind. The Centre will gather, develop and distribute knowledge on congenital deafblindness.

### JAPAN



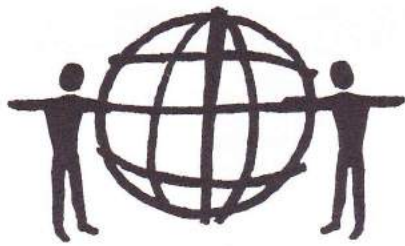
The first agency for deafblind people in Japan was established in 1991 with the National Deafblind Association. It is currently based in one office in Tokyo and receives funding from state subsidies, the Tokyo Government and independent donations. This limited space and budget restricts the Association to contact with 200 deafblind people, although it estimates that there are 24,000 deafblind people in Japan

who need its services.

Projects currently being undertaken by the Association include training interpreters for deafblind people, publishing a magazine and researching technical aids and education approaches.

In the future it aims to establish a service and rehabilitation centre dedicated to the needs of deafblind people.





I A E D B

## 11th World Conference

# Working and Growing Together

July 9 - 14 1995 Córdoba, Argentina

### Conference Announcements

1. When registering for the Conference please make cheques / money orders payable to  
"FUNDACION HELEN KELLER, CORDOBA."  
\*Do NOT make cheques payable to Hilton / Perkins or Perkins School for the Blind
2. Perkins is acting as a mailbox for the Conference, but please address anything to do with the Conference to:  
The IAEDB Conference Secretariat  
C/O Perkins School for the Blind  
175 N Beacon Street  
Watertown  
MA 02172  
USA
3. Please note the following changes to some of the Focus Days:
  - A. Usher syndrome.  
The Moyano family, Dr. Tamayo and Lic.Marta Rozo de Cortes will work with Mary Guest.
  - B. Families and their concerns.  
Stan Munroe (Canada) and Norman Brown (UK) will work with Alicia Picasso Cazon.
  - C. Early childhood.  
David Brown (UK) will work with Tom Miller (USA).
  - D. Services and Rehabilitation for Adults and Young Adults  
Marjaana Suosalmi (Finland) and Bob Snow (UK) will work with Silvia Romero de Fava (Argentina).

### NEW PUBLICATION

## DEAFBLIND EDUCATION: *developing and sustaining appropriate provision*

THE PROCEEDINGS OF THE  
1994 UK CONFERENCE  
ASTON UNIVERSITY,  
BIRMINGHAM

Tony Best leads the discussion with a paper on the challenges that are presented when planning and delivering services for this specific low incidence disability group of children. Other contributions are from education professionals and deal with the changing role of support services and special schools and present practical topics, such as, Objects of Reference, Intervenors in the Classroom and Access to the National Curriculum.

This is essential reading for all professionals concerned with the education of deafblind/multi-sensory-impaired children!

To order your copies, please send a cheque for £6.50 (including postage and packing) - made payable to 'Sense' and send it to:

Eileen Boothroyd  
Education Officer  
Sense  
11-13 Clifton Terrace  
Finsbury Park  
London N4 3SR.



# Communication with Usher People

One couple describe the effects of Usher on communication,  
and how they can be overcome.



**RUSS PALMER:** was born deaf and diagnosed with Usher syndrome at 21. He had an 8 year computing career before working as a Music Specialist with deaf and deaf/blind people. He has an 80% hearing loss and uses two high powered hearing aids. He uses speech, lip-reads and is learning sign language. His sight is very restricted, about 2 to 5 degrees (field of vision), and he uses the red and white cane while walking to assist mobility. He met Riitta Lahtinen in Sweden in 1991 while presenting a talk on Usher syndrome.

**RIITTA LAHTINEN:** is currently planning teaching materials for the deaf at the Deaf Association in Helsinki, Finland, she is a qualified teacher, interpreter and nurse. She has been working with deafblind people for 15 years and has specialist skills with Usher Syndrome people, after heading a project for 3 years. Riitta has full hearing and sight and has communication skills in English and Finnish, sign language (including "hands-on") and English deaf/blind alphabet.

## 1. Introduction

Ideas for this paper emerged from the relationship of these two people who became aware of different forms of communication for a couple. Their main forms of communication are:

- (a) English spoken language
- (b) English deaf/blind alphabet
- (c) Sign language (mixture of English/Finnish)
- (d) Body language and own gestures
- (e) English written language



## 2. Communication Problems

### (a) The Usher View

Russ was taught the "Oral Method" of communicating at a deaf school until the age of 7. He then attended schools which were integrated with hearing people. His contact with deaf people began at age 22 after he was diagnosed with Ushers.

Since hearing aids and radio microphones are only able to pick up some speech and lip-reading can prove exhausting, sign language and the deaf/blind alphabet are proving to be the most useful forms of communication, especially when the lighting situation is difficult.

It is important to understand that people with Ushers have to use a large amount of energy to communicate because of the concentration required. This applies to both deaf and hearing impaired Usher people who use sign language and lip-reading. The use of "hands-on" and tactile communication becomes the main source of communication as vision deteriorates over time. However, the development of "tactile touch and sense" is a slow process if one is used to speech.

Participation in group discussions may be necessary but impossible and one to one contact and appropriate lighting conditions are important to ensure the Usher person is able to see and follow these interactions properly.

Recognition of a partner's "body language" is difficult due to the Usher person's narrow field of vision; for instance, it is only possible to see the other person's face when looking directly at them. This situation becomes impossible when lighting conditions are difficult.

An Usher person may sometimes need some form of confirmation that another person has understood a conversation. Hearing impaired Usher people need to maintain eye contact while they are talking, compared to hearing people who can continue talking even when in different rooms. A visual sign, signal or response is necessary following conversation to prevent feelings of anger and frustration.

### (b) The Hearing/Sighted View

Hearing/sighted people use their ears and body language to communicate and do not have to use tactile communication. If a partner's spouse has Usher there are many problems the

hearing person may not be aware of, especially regarding communication. This can lead to mis-understanding, frustration, stress, pressures on the relationship and cause friction. Some of these problems are outlined below:

- (a) Repetition of own words can be very slow and takes much energy.
- (b) Repetition of other people's words can be time consuming.
- (c) Different forms of communication may have to be used in different environments.
- (d) If an Usher person is not used to tactile communication, the speed of communicating can be very slow.
- (e) The tone of the voice can be very difficult to hear when teasing and joking with each other.
- (f) Items in the home environment such as furniture, books, kitchen utensils etc. need to be kept in the same places.
- (g) The hearing/sighted person needs to tell the Usher person where they are moving to in settings.
- (h) Partners are often bumping into each other.
- (i) Guiding becomes a necessary way of life.

## 3. How to Improve Communication

The Usher person must learn to be independent as far as possible and not rely on other people to do things for them. It is important to consider that as the demands placed on the hearing/sighted person increase, more energy is required, causing tiredness. This can cause stress and pressure in a relationship or marriage. So the Usher person must learn to help in the daily living chores and to have specific responsibilities.

Another consideration is that both people should learn to be open with each other, to explore communication techniques and to discuss problems. Some suggestions follow.

### (a) One to One Communication

It is important to speak clearly and in a suitable lighting environment when communicating with hearing impaired Usher people so they are able to lip-read. If lighting conditions are difficult, the deafblind manual alphabet can be

used. For instance, use the alphabet for every first letter of a word, eg. use "B" for bedroom. This method saves a lot of time and energy in having to repeat words in conversation.

Depending on the situation or environment the Usher person can receive some form of feedback through touch (this is particularly useful in a dark environment). A gesture such as tapping for "Yes" / "Ok" and a rubbing from side to side for "No" / "What", can be done wherever suitable on the body. There are other methods such as placing the hand on the side of the face and feeling the head nodding for "Yes" or moving from side to side for "No".

Maintaining body contact allows the Usher person to feel safe and to know where the other person is, for instance touching the person's leg with a foot.

To indicate a direction or obstacle or even an aeroplane in the sky, the partner can get the Usher person to hold onto their hand or arm and point in the direction of the subject (see photograph).

The use of a video camera can be used at home and by professionals when running specialised Usher Rehabilitation Courses to help identify what forms of communication are or could be used.

### (b) To Get Attention (Distance and Direction)

These are suggestions on attracting someone's attention before speaking that saves both their energy, time and misunderstanding:

- Get into the line of vision first.
- Place the palm of the hand onto the Usher person's face and position head so eye to eye contact can be made. Some people find it difficult to co-ordinate where a sound or a vibration is coming from.
- Banging on the table or floor with a hand or foot to create vibrations.
- Waving a hand slowly from side to side at a distance.
- Blowing towards the person's face. This is particularly useful in a public place to avoid attracting attention.

### (c) Loving Relationships

An Usher person has to take off their hearing aids during the night time and communication may prove difficult. This is where both the deafblind



alphabet and hands-on gestures/signs are important to avoid frustration or misinterpretation.

If an Usher person develops a special loving relationship with a partner, it is very important for both people to understand and recognise the body language and responses that will develop as time goes on. Both partners should be open with each other and develop their own signs and gestures so communication does not become a problem.

Both partners need to show and express their feelings openly to each other particularly in a sexual relationship. The words "I love you" can have a deep emotional effect on both partners. It can also give the Usher person reassurance, security and self-confidence. It is difficult to pick up the signs and sounds of responses so each partner has to work out their own methods.

The need for human contact and companionship can be considered as a major priority for an Usher person. For example, on an Usher course in Birmingham, England, a 19 year old male asked "How can I ever have a girlfriend if I cannot take her to a cinema or disco, or drive a car? How do I tell her that I cannot see in the dark?". One has to reply by saying that he must not feel restricted, if she is a

nice girl or a good friend, she will help you.

Usher people are very sensitive; they need to feel loved, reassured and to be able to share in a loving relationship and probably regard this as an important area in their lives. Very often the "Usher" disability can be an obstacle especially when one considers their "Quality of Life". The need for social groups and clubs have a vital role in providing friendships for Usher people.

## 4. Conclusion

We think that the priority of partners is to have a common language, whether it is a spoken, signed, deaf/blind manual alphabet or gestures, so that they are able to communicate in the best possible way. This language should allow both people to communicate in any environment, whether at home or in noisy atmospheres. To find this language requires patience, understanding, listening and a willingness to be open and share experiences.

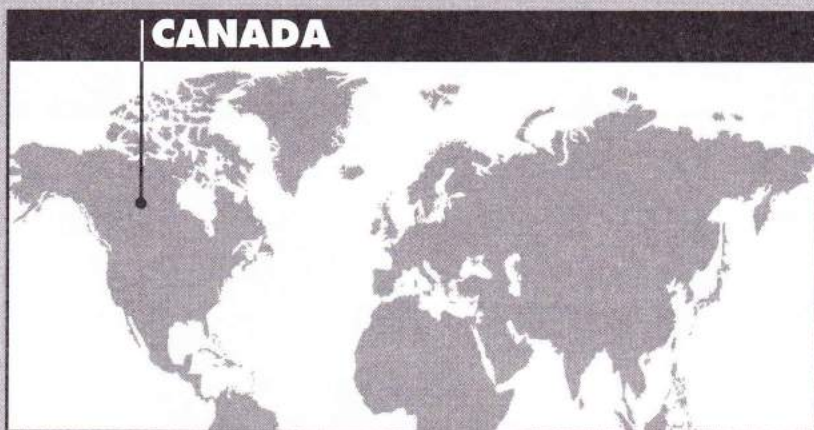
Partners need to work out individual signals, signs and gestures through using different forms of communication. They need to practice regularly and learn from each other as

it is a two way process of learning.

Relationships and marriages may very often break down where there is an Usher person involved due to a lack of communication between partners. It is necessary for couples to become aware of the changes and adaptations that will be required when the Usher person's vision or hearing starts to deteriorate. They have to be able to share and talk openly about the little problems which they have to cope with during any changes of sight and/or hearing.

Each partner needs to have time alone. Other friends and social groups are necessary so they can pursue their own interests with other people. They must not feel totally dependent on each other, this can in many ways make a relationship or marriage stronger.

Neither person in a relationship should be dominant, they should try to give and take, to help each other with domestic chores no matter how small. Usher people are not "disabled" (in their own thinking), they just have restrictions in their hearing and sight, and need to have additional support if they get into difficulties. They are quite capable of doing anything, it is a matter of learning to change and be encouraged to do things in a different way, to have faith and courage.



Funding for 3 new independent living facilities for congenitally deafblind adults was granted by the Ontario Government in 1993. Canada now has over 12 such facilities to provide quality living experiences. The Government also funds 12 home based services enabling deafblind individuals to

have year - round programmes provided in their own homes.

The western region of Quebec has expanded its services for deafblind people. Individuals of all ages living in this large region with a population of 4.7 million can access adaptation and rehabilitation services provided by the *Institut Raymond-Dewer*

*Rehabilitation* in Montreal. In 1993 this served 177 deafblind people.

A philosophy of integration is advocated in Quebec and encourages parents to live with their child who is deafblind. This is supported by an expanded programme of intervention funded by the Ministry of Health and Social Services.

The fourth Canadian Conference was held at New Brunswick in June 1993. Its theme was "Caring enough to let them grow". This was attended by a international mix of professionals and its proceedings will be published in 1995. The fifth conference is currently being planned for May 8 - 11th 1996.

**Stan Munroe**  
President  
CDBRA



# Development of Interpreter Services in Europe

**M**uch is happening in Europe regarding interpreter services for deafblind people. There have been discussions within IAEDB on this subject and in early 1994 a committee was formed to look at the benefits that international collaboration could bring to the development of these vital services.

Its goals are:

1. The establishment of a European network of people responsible for the development of interpreter services.
2. The production of a document detailing the situation in every country.
3. The development of a curriculum and identifying the subjects that are of most importance within the different services.

Great steps towards achieving these goals were made at a seminar on the Development and Training of

Interpreters for Deafblind People in Lisbon in September 1994. The seminar was organised by Casa Pia (Portugal), Lega del Filo d'Oro (Italy) and the EUUCO Unit and was partly funded by a grant from HELIOS, the European Union's disability programme.

The seminar was the first international activity concerning deafblindness to be held in Portugal and involved representatives from 12 countries. Antonio Rebelo from Casa Pia said that the TV and press coverage of the event went a long way towards promoting the activities of deafblind people and the importance of interpreters.

One important issue to arise from the seminar was the acknowledgement of the necessity for interpreters to have academic, psychological and ethical training in addition to sign language, braille, guidance and mobility training.

The committee will meet again in May in Denmark to start putting



**William Green**

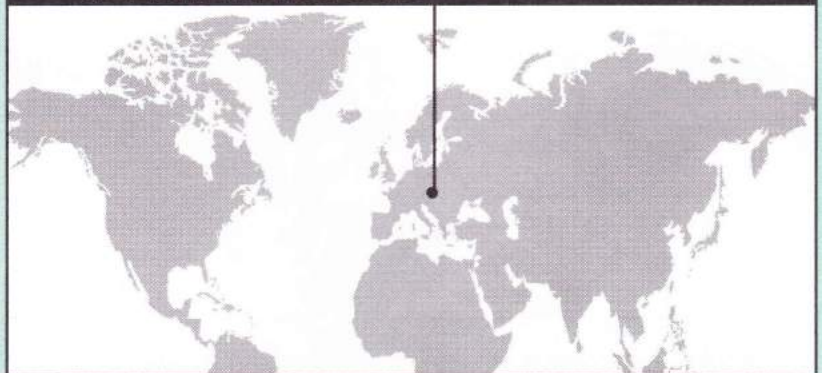
together more detailed information and produce a pack which will be available to anyone interested.

For more information please contact William Green at *Lega del Filo d'Oro*.

In 1991 there was no governmental or non-governmental organisation in the Czech Republic that systematically recorded instances of deafblindness. Since then the Association for the Deafblind (LORM) has registered approximately 300 people who are deafblind and planned a comprehensive programme of activities.

LORM was established in 1991 and held its first General Meeting on 12th November 1994 in Prague. As an independent organisation it strives to overcome communication differences and degrees of handicap amongst its members to ensure everyone can participate equally. This supports the principle of ensuring development programmes are decided and exercised by people with disabilities which is gaining momentum across Europe.

## CZECH REPUBLIC



The "LORM Service" is attached to the Institute of Social Care in Kamarád which has seven centres across the country. It has provided ten psycho-rehabilitation courses for people who are deafblind and has totalled attendance numbers of almost 200.

LORM has overcome many obstacles to achieve this progress and recognises that continued perseverance will be necessary to achieve its plans for the future. Contact Jan Jake at LORM for further information.



# The Development of Services in India

**One specialised service for deafblind people in a country of almost one billion people is certainly not enough, but recent developments bode well for the future of deafblind services in India.**

**Summaries of the situation for deafblind children and adults have been produced by Mrs. Beroz Vacha, Director of the Helen Keller Institute, and Mr. Rajinder Singh Sethi, a deafblind man from Bombay.**

**In this focus on India Richard Hawkes, Sense International Officer, presents these summaries and outlines plans for the future.**



**Mrs Beroz Vacha, Director, outside the Helen Keller Institute**

## Education of Children

It is only in the last 20 years that educationalists in India have started to consider the philosophy of Total Communication.

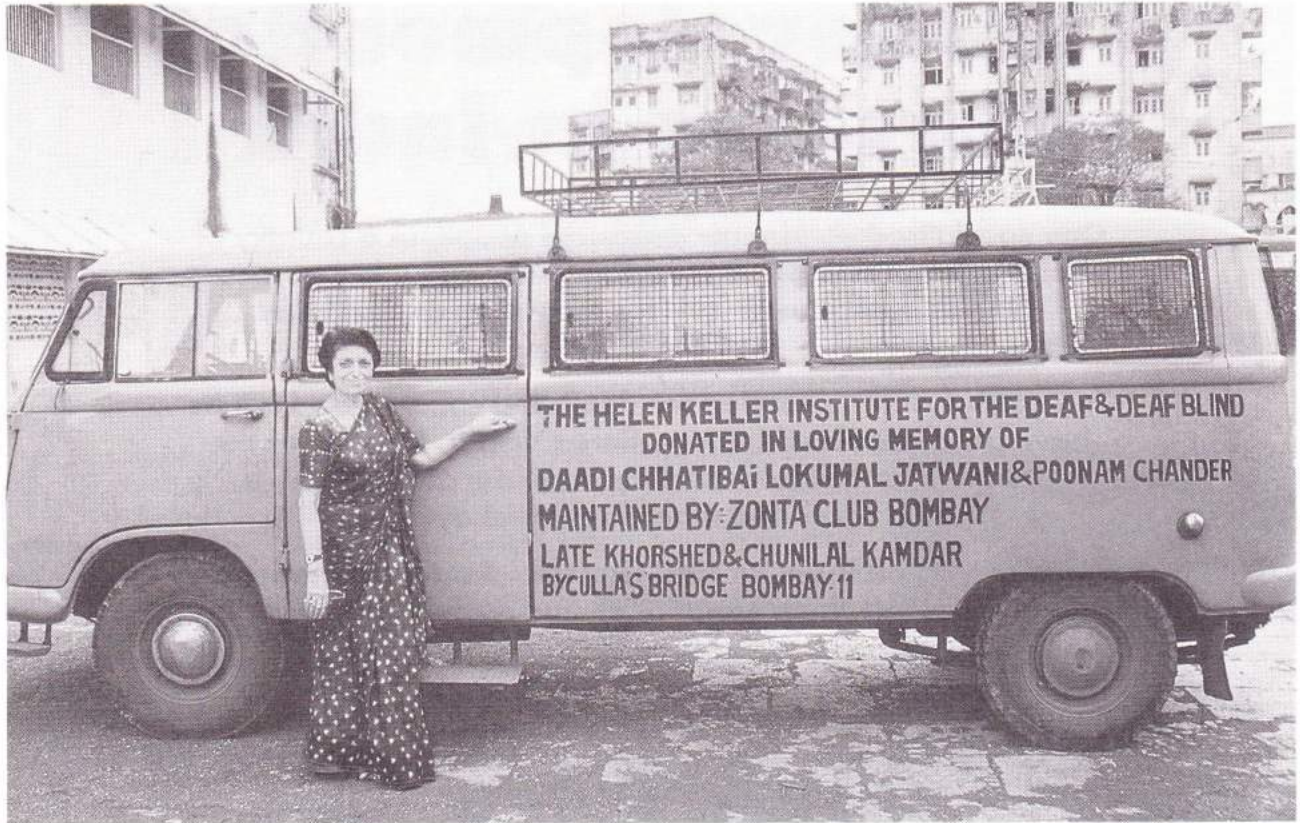
The concept of providing every child with access to a better quality of life and a purposeful way of communicating drove the establishment of the Helen Keller Institute for the Deaf and Deafblind Bombay in 1977. It was the first institute in Asia to educate deaf and deafblind people using the philosophy of Total Communication.

The Institute started in the home of one of the teachers with an initial budget of 150 Rupees (about \$US 5) and provided for two deafblind children and one deaf child. The initiative came from Beroz Vacha who, as a teacher of the deaf, met a child who was deafblind. Since Beroz was committed to the concept of education being a fundamental right of every child she determined to establish a service which would support the needs of multi-sensory impaired children.

The school offers individualised teaching strategies to meet the needs of each child. The programmes concentrate on:

- Literacy (learning to read and write braille)
- Mobility (exploring the environment, using a stick)
- Body awareness
- Self care and self help skills





**Mrs Beroz Vacha, Director of the Helen Keller Institute**

- Pre-vocational opportunities
- Cognitive motor skills

Most of the 22 deafblind children presently at the school live in a residential centre approximately one hour's drive away from the school.

The Helen Keller Institute is committed to starting programmes and giving free educational advice to any institute that invites them. The first such project was in 1985 when assistance was given to the Singapore

School for the Blind to start its first programme for deafblind children. More recently, in 1990 the National Association for the Blind in India referred three deafblind children from its centre in Delhi. With the support of the Hilton / Perkins Program the Helen Keller Institute trained one of the teachers from Delhi and a programme has now started.

In 1993 the Institute was allotted one acre of land in another part of Bombay by the Regional Government.

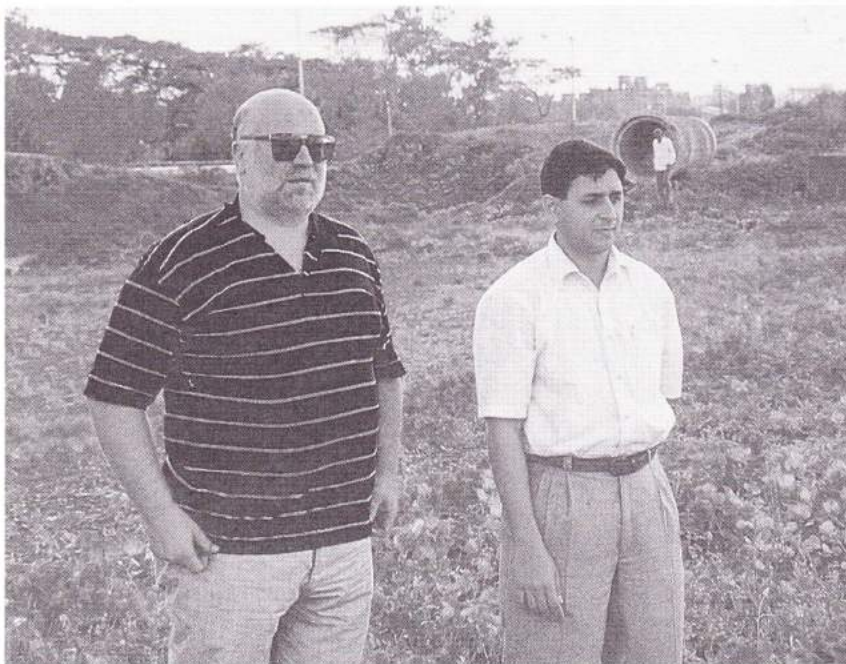
The plan is to build a new centre which will house the school, accommodation for the children, group homes for young adults, a family advisory service and an assessment centre.

"The ultimate goal" says Beroz Vacha, "is to make the handicapped child, regardless of his handicap, a functional human being within his field of abilities. There can be no greater test for the measure of an individual, society or a nation than the way in which we individually and collectively care for our children."

## The Status of Deafblind Adults

"Handicapped people usually have difficulties adjusting to life in a world generally meant for normal people. Of handicapped people, the lot of the deafblind is really the worst" claims Rajinder Singh Sethi, himself a deafblind man.

In India there has never been an official survey to determine the number of deafblind people. A few organisations have tried to find out how many of the blind population suffer from hearing impairment. It was found that between 1 - 2% of the blind and visually impaired population of over one million also have hearing problems. This does not take into consideration people identified as deaf



**Rodney Clark (Sense) and Xerxes Pithawalla, architect for the new building on the allotted site of the new building**



who may have additional visual impairment and people who are deafblind but are not included within either the blind or deaf populations.

In general the adult deafblind population has to undergo many hardships. In India there are hardly any social security benefits for disabled people and, clearly deafblind people will encounter difficulty in obtaining employment. "There was a lot of fanfare and publicity when I obtained my doctorate" says Rajinder Singh Sethi, "but nobody has yet come forward to offer me a job." It is a similar situation for other deafblind people.

To begin to achieve a meaningful life Rajinder Singh Sethi believes that first deafblind people should be accepted by their families, then by society, associations and government. Rehabilitation measures need to be designed to suit individual needs, and the "fatalistic" attitude of people needs to change to a more practical and scientific approach.

## The Future and the Involvement of Sense International

In March 1994 Sense created an International Office with the primary aim of assisting the growth of deafblind services in countries where these are underdeveloped. For many years there has been a close relationship between Sense and the Helen Keller Institute. This is one of the reasons the Sense Council agreed the first substantial development projects for Sense International should be in India.

Richard Hawkes and Rodney Clark visited India in July 1994 to discuss the possibility of developing a programme throughout India. With the support of the Helen Keller Institute and a number of other relevant governmental and non-governmental organisations firm plans are now established for the future.

In 1995 John Hatton, Director of Sense West (formerly Sense Midlands) will be undertaking a three month exploratory visit across India. Sense will then be appointing a Development Manager for India, to be based in Bombay, to undertake a detailed review of the situation, identify partners for collaboration, assess possible locations for future service development and establish a Sense India Committee. It is hoped that this groundwork will lead to the emergence of services in other towns and cities in the next three to four years.



**Going for a walk outside the Helen Keller Institute.**

Sense International is keen to develop partnerships with any organisation, institution or school wishing to share our goal of providing improved services for the deafblind children and adults of India. Work is being closely co-ordinated with the Hilton / Perkins Programme who have been involved in India for a number of years, and Beroz Vacha who will be

acting as a Consultant for the programme. For more information please contact:

Sense International Office  
The Princess Royal Centre  
4 Church Road  
Edgbaston  
Birmingham B15 3TD  
United Kingdom.

### **Ann Barnett, former director of the National Deafblind League in the UK, communicating with two students of the Helen Keller Institute**





## PACIFIC ISLANDS

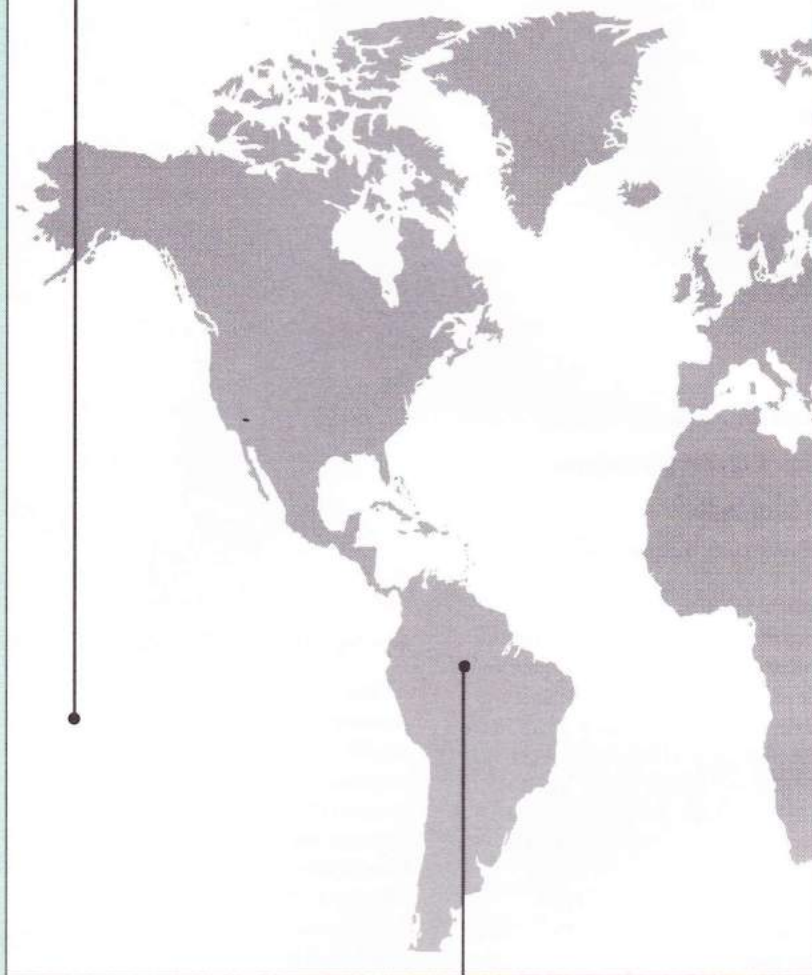
In the developing nations of the Pacific there are fresh and fragile infrastructures which do not facilitate the collection of data on disabilities such as deafblindness. The establishment of such mechanisms is a low priority and is fraught with the difficulties brought by a scattered population with a diverse geography. The high concentration of different languages in each island further hinders defining and identifying numbers of deafblindness.

Fiji, the most developed nation in the region, has had a School for the Blind since the 1970's. However, access to this service by island populations is limited due to a lack of communication and travel resources. Blindness is increasing at an alarming rate in the region and the national Government is ill-equipped to provide a service with only one ophthalmologist serving the population of 4,000,000.

The common perception of the Pacific islands is one of lush tropical resorts and an idyllic lifestyle. In reality there is a population with a high proportion of malnutrition and poor sanitation. These contribute to the growing incidence of blindness, most of which is preventable or curable.

The Pacific Islands' Council for Blind Persons has been developed to address these issues. As a consortium of nine islands it is working to develop greater understanding and support for preventing and curing unnecessary blindness. It is looking to agencies and corporations in developed countries to assist the funding of these services. Contact Bill Winkley at the *Pacific Islands Council* for further details.

# COUNTRY REPORTS



## LATIN AMERICA

The "Programme to create an organisation of deafblind persons in Latin America" (POSCAL) was initiated by Yolanda de Rodriguez from Columbia and Graciela Ferioli from Argentina following research which revealed there are a considerable number of deafblind people in Latin America and a lack of knowledge about their needs.

There are no precise figures for the number of the deafblind persons in Latin America. Although there are 67 institutions that provide services for deafblind people, only a few are specifically

designed for their unique needs. Only 5% of teachers attached to these services have appropriate training for teaching the deafblind, and there are no interpreter facilities. This highlights the critical situation in Latin America and the need for a project to address it.

The first meeting of the POSCAL group will develop a programme for the Andean Region countries of Bolivia, Colombia, Ecuador, Peru and Venezuela. It will be held in Bogota in February 1995. Enquires should be addressed to Ximena Serpa at POSCAL (fax 57 1 211 87 66), or Yolanda de Rodriguez (fax 57 1 620 17 39).



# Neuropsychological Aspects of Communication and Development

## Consequences for educational training of the deafblind

Hans M Borchgrevink - The National Hospital University of Oslo, Norway

### On Brain Development

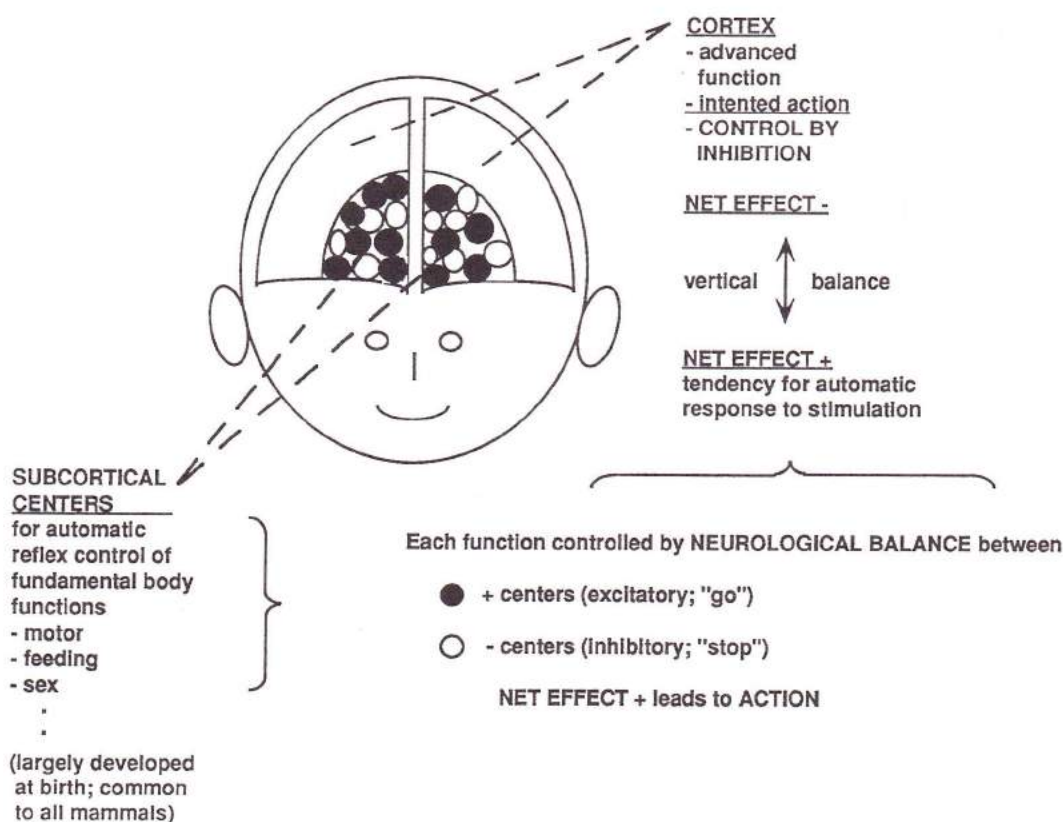
The infant is born with an immature brain cortex. The cortex is essential for advanced motor function, cognition, learning, communication and flexible control of behaviour. Fundamental physiological functions are largely controlled by pre-programmed

lower (subcortical) brain centers, tuned to respond to stimulation by automatic reflex actions (e.g. sucking). These subcortical centers are well developed at birth. Therefore infant behaviour is dominated by automatic reflex responses to stimulation and has poor impulse control. With increasing age, biological cortex maturation gradually makes the

cortex more efficient. The child masters more and more advanced functions - reflected in psychomotor development - and has improved control of behaviour by cortical inhibition of automatic reflex behaviour (see figure 1 below).

Frontal cortical damage characteristically leads to motor disorder, impaired concentration,

Figure 1





initiation and/or response (impulse) control.

Under reasonably normal environmental conditions, age related cortex maturation limits psychomotor development: the effect of training is far lower than most people like to believe. For example, one twin trained at stair-climbing from age 46 weeks, managed in 26 seconds at age 52 weeks. The untrained twin was introduced to stair-climbing at age 53 weeks, and climbed the stairs in 10 seconds at age 55 weeks. In the following weeks one twin was trained in cube-stacking, but after 6 weeks of training did no better in terms of speed or number stacked than the untrained twin (*Gesell & Thompson 1929*).

Correspondingly, children with delayed or deviant behaviour seldom catch up with, and pass, the performance level of normal children in spite of additional training (*Hallaban & Cruickshank 1973; Borchgrevink 1989*).

## Diagnostic and Paedotgical Consequences - in general

Significant psychomotor delay later than 90-95 percentile that does not normalize rapidly upon training, signals organic brain damage. Organic brain damage largely affects the cortex and reduces a person's capacity and potential to benefit from educational stimulation or to take part in social intercourse, unless these are adjusted to his capacities. Dead brain cells and cut fibres are never replaced or restored. Function is thus permanently impaired, and can not be normalized by training, but will improve with age and brain maturation throughout puberty within the limits set by the remaining brain cell/fibre network.

Different parts of the brain control different functions. Brain damage may be localised or more generalised, and may lead to slight or severe impairment of

perception, cognition or behavioural function, alone or combined. To be effective, stimulation should be tuned to just within the limits of the person's capacity for each sub-function.

Planning of educational training thus requires an evaluation of the person's "profile of function": his cognitive capacity (mental age level), and a comparison of the developmental age level for each perceptive and expressive channel. Since organic brain damage can not be cured by training, the educational effort should utilise his resources instead of focus on his defects, and aim to compensate weak sub-functions by the use of stronger functions.

Sufficient, "good enough" stimulation should be presented via the best perceptive channel which transmits the most advanced information most efficiently to the cognitive level. Logically, the person's true cognitive capacity can only be reflected by - and reached by - their best perceptive channel. In the case of (left

Figure 2

### OUTPUT

MOTOR  
EXPRESSIVE  
RESPONSE CONTROL

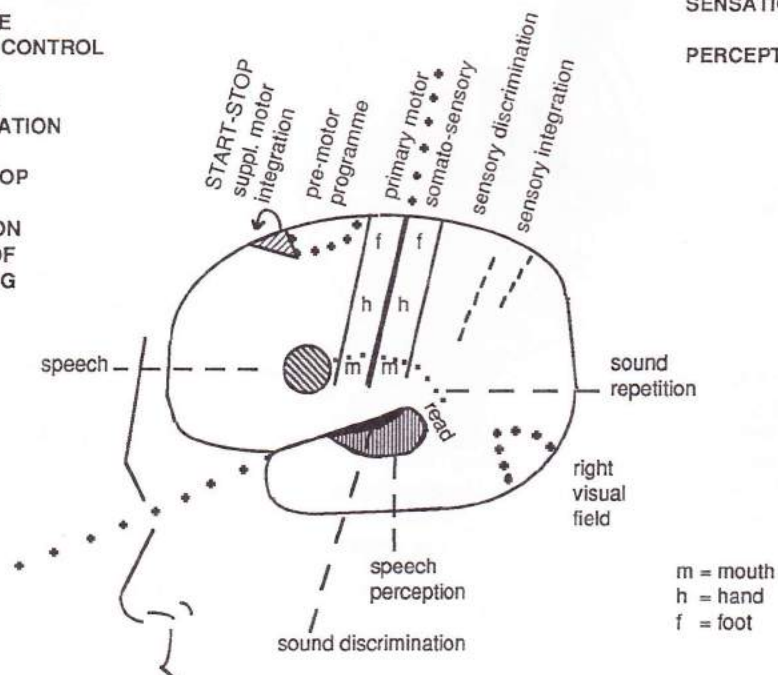
ATTENTION  
CONCENTRATION  
INITIATION  
START - STOP

INTEGRATION  
CONTROL OF  
PROCESSING

### INPUT

SENSATION

PERCEPTION





hemisphere) verbal speech/ language problem, autism or mental retardation, iconic visuocognitive (right hemisphere) stimulation, e.g. pictograms/iconic signs, are often the most efficient, as it has low demands on the advanced functions that tend to be first and most seriously impaired. These are memory span, concentration and coding/decoding (see figure 3 below). One must evaluate the level and quality of dysfunction in the functions specific for the most important communicative channels (fig. 4). A neuropsychological assessment procedure for mental age 7 years has been developed by Gjaerum and Borchgrevink and is under standardization (Borchgrevink 1989).

## Diagnostic and Paedagogical Consequences - in the deaf-blind

The deaf-blind person has combined organic impairment of the two most important perceptive channels often combined with other neurological psychomotor handicaps and mental retardation. By and large, most dysfunctions are different manifestations of the same organic brain damage - induced by the disease that caused the deaf-blindness. Thus, the motor disorders and learning disabilities observed in the deaf-blind are most often *not* secondary to the sensory deprivation caused by the deaf-blindness, especially if increased stimulation fails to increase the developmental level or rate.

Stimulation and education can only give improved sub-function within the person's neuropsychological capacity or

potential. Total visual deprivation leads to irreversible affection of visual perception. Studies on paediatric cataract (opaque lens preventing visual stimulation to an otherwise normal eye and brain) show lifelong, irreversible organic impairment of central visual pathway development - and impaired visual acuity/perception - if not operated before 3 months, and leads to persistent blindness if operated after 7 years of age (BenEzra 1990). This clearly demonstrates the importance of early intervention/stimulation upon brain development. Corresponding auditory impairment effects are expected, but not yet shown or published, for deaf children treated with cochlear implants at an early age. In total deaf-blindness the tactile channel will largely be the best channel (fig. 4). In combined auditory and visual perception deficit, the iconic visuocognitive stimulation may often prove to be most efficient (fig. 3).

Figure 3

### HEMISPHERE SPECIALIZATION

#### RIGHT

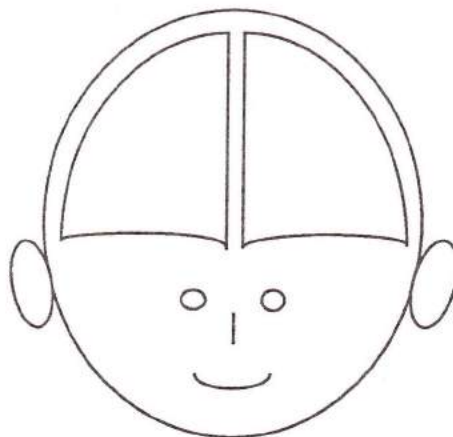
pitch  
chord  
visuospatial  
form  
figure  
spatial

#### ICONIC SIGNS

- the sign refers to a meaning
- the sign demonstrates the meaning

- low demands on
- memory span, as single holistic pattern
  - concentration, as analyzed in a "glimpse"
  - decoding of concrete relation sign - meaning

SIMULTANEOUS PATTERN  
e.g. chord, figure



#### LEFT

speech perception  
speech production  
prosody (tone pattern in speech)  
rhythm  
reading  
writing

#### PHONETIC SIGNS

- the sign refers to a sound, not a meaning

- high demands on
- memory span, for sequence pattern
  - concentration during sequence analysis
  - decoding of abstract relation sign - meaning

SEQUENTIAL PATTERN  
e.g. rhythm  
speech  
word



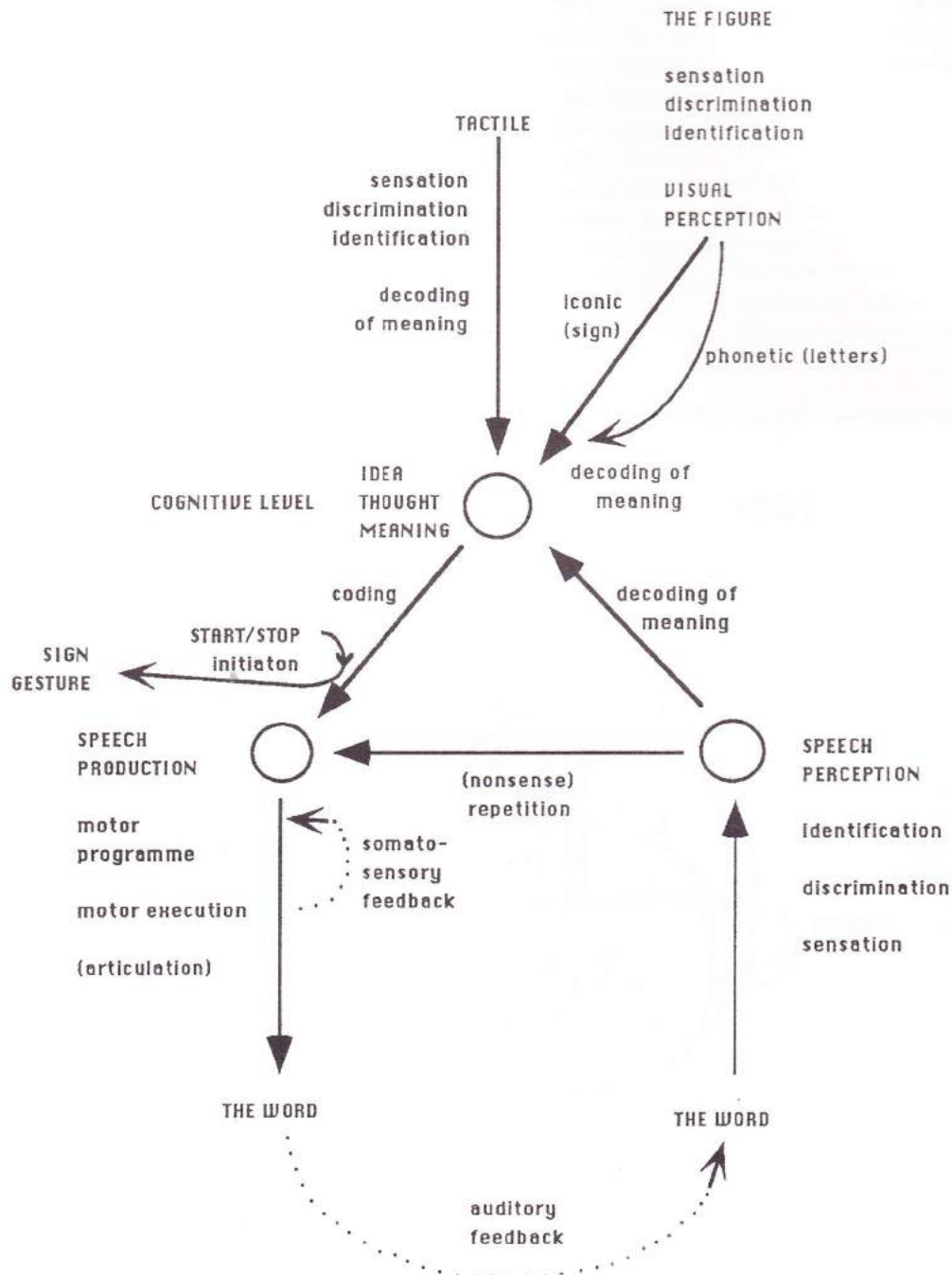
## Conclusion

As a basis for choice of assessment, one should perform a neuropsychological mapping of level and quality of function for all important sub-functions including memory and concentration / initiative and response control under relevant environmental situations. Adjust the educational

programme / the stimulation profile (this is the amount, type, quality and level of stimulation effort given in each channel/sub-function) to his profile of function (this is the level and quality of sub-function just mastered for each subfunction). For example, if the child has a memory span of 2 units, all information must be given in two-unit short messages (e.g. two-

sign sequences) in order to be perceived. Make sure to give good enough stimulation via the best perceptive channel. Utilize the best perceptive and expressive channels in the modes that allow transmission of the most advanced information. Compensate for delimiting sub-functions.

Figure 4





# The EUCO Unit

## The European Coordinating Unit for Staff Development in Deafblind Services



**The EUCO unit offers information and coordination services to those who train and develop staff to deafblind people. You can subscribe to these services.**

Subscription automatically ensures:

- Membership in the European network cooperating on staff development in deafblind services
- Information on actual work and events of relevance to staff development through The EUCO News Bulletin
- The bibliography of NUD's international library on deafblindness and related topics
- An updated inventory once a year. Here you will be able to find, at

least as the network develops, the resource persons that you would like to contact, visit etc.

The subscription fee for a corporate membership is 100 ECU per year for organisations / institutions / schools / individuals in general.

For those of you who do not wish to subscribe it is still possible for you to be registered in the Inventory - Directory of Resources and then order a copy of it. It holds information of 119 organisations, institutions, schools and individuals, in Europe and other parts of the world providing services for

deafblind persons. It has information about a number of professionals in deafblind work and their current projects. It also contains four charts which give an overview of the services and programmes offered to deafblind persons.

For subscriptions to the services of The EUCO UNIT, or for entries to the Inventory please contact us at:

The EUCO Unit  
c/o NUD  
Slotsgade 8  
DK-9330 Dronninglund





## THE EUCO UNIT

### Coming Events

# Outdoor Activity Week for Deafblind Youth

An outdoor Activity Week for Deafblind Youth has been arranged to take place from 9 June to 16 June 1995, in Aalborg, Northern Jutland, Denmark. The organizers are Institutionen for Døvblinde (The Institution for the Deafblind), Aalborg, and The EUCO Unit, Dronninglund, Denmark.

This activity week is arranged in order to give professionals in a multidisciplinary team, e.g. teachers, training staff, physiotherapists and occupational therapists, the opportunity to gain the necessary skills to enable deafblind youth to participate in outdoor activities. There are many activities to choose among, e.g. fishing, tandembicycling, horseback riding, swimming & sailing

**YOU ARE WELCOME TO JOIN  
THIS VENTURE!**

The participants will be European deafblind youth, aged between 15 and 30, accompanied by their staff. The total number of participants will be approximately 40. The deafblind participants may be accompanied by one staff member/interpreter only.

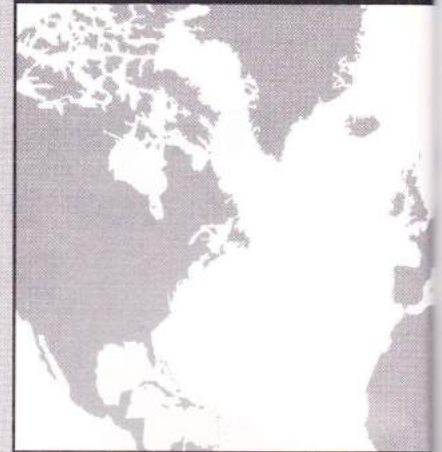
The event will be financially supported from Helios, which means that the arrangement, i.e. board and lodging and activity programme, is free of charge. Participants pay their travelling expenses only.

For further information please contact:

Preben Gundersen  
Institutionen for Døvblinde  
Tel: +45 98 14 45 77  
fax: +45 98 14 73 44

or The EUCO Unit c/o  
Tel: +45 98 84 34 99  
fax: +45 98 84 34 88.

ITALY



### Presidential awards for workers with deafblind people

On 7 November 1994 the President of Italy, Luigi Scalfaro, recognised the 30th anniversary of the Lega del Filio d'Oro by awarding honours of the highest order to the people instrumental in the development of the association.

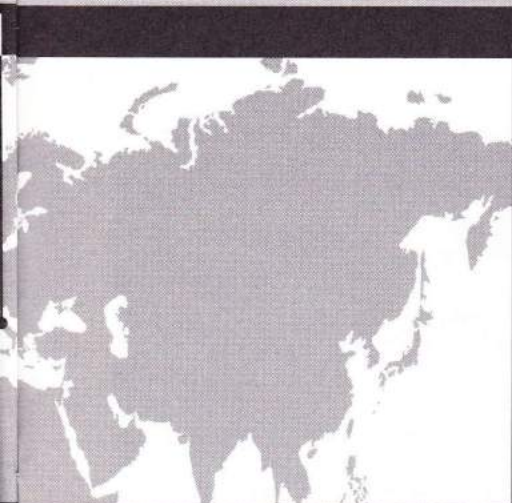
The four recipients of the award



*President Scalfaro presents  
the awards*



## CONFERENCE NEWS



for 'Grand Officers of the Republic' were Sabina Santilli and Dino Marabini, two of the founders of the Association, the President of the Association Mr Guida De Nicola and the Mayor of Osimo, Mr Raimondo Orsetti.

125 children, families and professional from the "lega" were invited to participate in this important ceremony which took place in the Presidential Palace in Rome.

For the students and their families it was a great experience to be able to meet personally "Il Capo della Stato".



# Deafblind Children and Communication

**2 - 4th June 1995, Trento, Italy**

In 1995 the **Servizio Di Consulenza Pedagogica** will hold its 18th event for parents of deafblind children. This year it will be a three day conference held in Trento, Italy.

The conference will focus on raising awareness of the need for deafblind children to express themselves through various communication channels:

"Communication enables a culture to be transmitted and people to share their thoughts and feelings."

Parents and professionals working with deafblind children will be invited to share their knowledge of communicating with deafblind children.

All participants will receive a copy of *"Bibliography on Languages and ways to communicate used by Deafblind People"*.

For further information please contact:

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Servizio Di Consulenza Pedagogica  
C.P. 601  
I - 38100  
Trento,  
ITALY

Telephone (0039) 461 828693





# Reorganising the IAEDB

## The Strategic Planning Process

The Strategic Planning Working Group was formed at the Executive Meeting in Poland in April 1994 to develop a series of options and recommendations regarding the future of IAEDB. It has now had its first meeting.

A detailed paper will be circulated to all members of IAEDB to ensure a wide input to the decision process. The Working Group has agreed the following procedure:

1. The options and recommendations discussed by the Working Group are circulated to all members, in the form of a questionnaire, before the World Conference in Cordoba, June 1995.
2. The Working Group meets in Cordoba to identify Consultation Groups and Group Chairs. These Groups will be formed according to language not geographical regions.
3. The options paper is presented to the General Meeting in Cordoba.
4. Briefing of Consultation Group Chairs.
5. Delegates to the World Conference discuss the options in Consultation Groups.
6. Tony Best and the Consultation Group Chairs meet to discuss the outcomes of the Group discussions.
7. Tony Best summarises the discussions, with contributions from the Group Chairs, in the summation speech to the World Conference.
8. A questionnaire is circulated to every IAEDB member. (This is to ensure an input to the process from all those unable to attend Cordoba). These must be completed and returned by November 30th 1995.
9. The Working Group and the new IAEDB Officers meet again in January 1996.
10. Final, constitutional decisions are made at the Executive Meeting in Canada, 1996.



# IAEDB

The International Association for the Education of DeafBlind People was founded over 30 years ago to promote the education of deafblind children and young adults throughout the world.

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

## The objects of the Association as established are as follows:

- To promote the recognition of deafblindness as a unique disability throughout the world.
- To promote the education and development of deafblind people throughout the world in accordance with the educational and administrative requirements and with the socio-economic circumstances of individual countries, states and authorities.
- To guard and strengthen the civil rights of deafblind people and to ensure their equality of opportunity with other citizens.
- To promote continuing and life-long education and development for deafblind people.
- To promote and make known the variety and diversity of social support systems for deafblind people throughout the world.
- To promote interaction within the community of deafblind people.
- To promote interaction between deafblind people, their families, professionals and the wider community.
- To gather and disseminate information on research, staff development and programme methods.
- To promote research.

The phrase "deafblind people" is intended to encompass all age ranges, from childhood to old age, and all conditions of deafblindness, whether acquired congenitally or adventitiously.



**International  
Association  
for the  
Education of  
Deafblind People**

**JOIN  
NOW!**

## Membership

There are two categories of membership: **individual** and **corporate**.

**Individual membership** is open to anyone and is without charge. An annual donation of £10/US\$20 is requested. Each country can have a representative on the Executive Committee for every 10 individual members. There is a maximum of three representatives.

**Corporate membership** is open to any school, association, institution, society or any similar organisation. There is an annual subscription of £100/US\$200. Each corporate member can have one representative on the Executive Committee.

All members will receive *DeafBlind Education* and may vote at General Meetings at the World Conference.

Please return this to IAEDB, c/o Sense, 11-13 Clifton Terrace, Finsbury Park, London N4 3SR, United Kingdom.

I wish to become an individual member of IAEDB. I enclose £10/US\$20, or

I wish to become a corporate member of IAEDB. I enclose £100/US\$200

Our corporate representative will be \_\_\_\_\_

Signed \_\_\_\_\_

Name \_\_\_\_\_

Institution \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

Tel \_\_\_\_\_ Fax \_\_\_\_\_





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