

The Internet, the World Wide Web and Deafblind People

pages 7-8

Some aspects of rehabilitation

pages 12-14

Focus on CHARGE Association

pages 9-10



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 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.

Editor Malcolm Matthews

Editorial Team Anna Cartwright
Richard Hawkes

Editorial Office Sense
11-13 Clifton Terrace
London N4 3SR
United Kingdom

Tel: +44.171.272 7774

Fax: +44.171.272 6012

LAST COPY DATE FOR THE NEXT EDITION: 20 September 1996

MESSAGE FROM THE CHAIR

While writing this message I am excitedly waiting for the Reception at Buckingham Palace to commemorate Sense's 40th anniversary. The invitation has come from HRH The Princess Royal, who is patron of Sense, the National Deafblind and Rubella Association in the UK, and who has supported and encouraged Sense's work for many years. This gives me a great opportunity to thank Sense for its valuable work for IAEDB during all these years. I can say without exaggerating a bit that without Sense's, and especially Rodney Clark's, contribution we would not have the same IAEDB as we have today. I do not mean only all the hard work and support Sense has donated, but also their role in creating an atmosphere of togetherness and friendship which is quite unique. Thank you Sense and all who have done so much valuable work for the IAEDB! Thank you Rodney!

But life is not all celebrations, and some people have to work. Around the same time as this event, 55 people from European countries gathered in Poitiers, France, for the European Seminar on Acquired Deafblindness. The work with adventitiously deafblind has not traditionally been IAEDB's



concern, but now the professionals working with people with acquired deafblindness have found IAEDB a useful forum for international discussion, and we are happy to support this. Two papers presented during this seminar by Ann Svensson and Ole Mortensen are included in this edition. The Seminar was organised by the IAEDB sub-committee on acquired deafblindness together with the French organisations APSA and ANSPA.

In January two important meetings were held outside Lisbon, in Portugal. The first was the meeting of the IAEDB Strategic Planning Group. The

suggestions of this group are now being prepared for the Executive Committee meeting in Vancouver, Canada, to be held in May, and are presented on page 8. These proposals have been thoroughly considered and will provide a useful document for decision making. I would like to thank the group for its good work. During their collaboration it became evident that we need a special group for strategic planning in the future as well.

The second meeting was the International Partners' conference. Many agencies and organisations gathered for state of the art debate and co-ordination (see page 5). This meeting, which was initiated by Sense, was felt very useful and should be repeated occasionally.

Summer is fast approaching here in Europe. This summer there will not be a big IAEDB conference - but comforting enough is the first announcement of the European conference to be held in Madrid in 1997, and awareness that colleagues in Portugal are preparing for the next world conference in 1999.

Marjaana Suosalmi

CONTENTS

NEWS

POSCAL page 4

Pioneering course in Western Australia page 4

**International Partners' Meeting of Organisations
Working Internationally in the
field of Deafblindness
page 5**

Conference at NUD on Cochlear Implant page 6

**Notice of Nordic Conference
on Deafblindness page 17**

**IAEDB Strategic Planning Group
Report to Executive page 18**

FEATURES

The Internet, The World Wide Web and Deafblind People

An exposé on how to access the Internet and its potential for deafblind people.

pages 7-8

Conditions and Syndromes that can result in Deafblindness

The second in our series of reports examines CHARGE Association.

pages 9-10

Some Aspects of Rehabilitation

The role of family rehabilitation is evaluated as a component of effective deafblind rehabilitation.

pages 12-14

Basic Services for the Elderly Deafblind: Surveys and Statistics

A series of international surveys into acquired deafblindness in elderly people are examined.

pages 15-16

COUNTRY REPORTS

Uganda page 11

Slovakia page 17

EDITORIAL



In many countries acquired deafblindness is an increasingly important topic because of demographic

changes and improvements in health and health services. The European Commission recently published a report setting out the scale and speed of the ageing process. According to the Commission, the number of Europeans aged over 60 is set to double by the year 2025. By that date there will be 113.5 million over-60s in the European Union – making about a third of the total population. Few people are aware of the extent of this increase and what it will mean.

This rise is important in talking about deafblind people because in Europe the majority of deafblind people are elderly and a significant increase in the elderly population means an increase in the deafblind population. We are only just beginning to recognise the extent of deafblindness among the very elderly. The subject of persuading government and agencies of the need for services to deafblind people and the range of services required is a very difficult task. Ole Mortensen discusses this expanding population on pages 15-16.

By the time you read this the IAEDB Executive will have met in Vancouver to consider the future direction and strategic development of the organisation. The meeting will have considered the discussion on this topic at the last World conference in Cordoba, the results of the consultation exercise, and the deliberations of the Strategic Planning Group led by Tony Best (presented on page 18). I look forward to being able to inform you of its conclusions in the next Deafblind Education.

Don't forget to send in your contributions, whether news or articles!

Very best wishes.

Malcolm Matthews

P.O.S.C.A.L.

In issue 14 of Deafblind Education details were given about POSCAL – the Project to Create Associations of Deafblind People in Latin America. Ximena Serpa, POSCAL Co-ordinator, provides an update on the situation.

POSCAL is sponsored by the Federation of the Swedish Deafblind (FSDB) and Swedish Handicap International Aid (SHIA) and is running in five countries in Latin America. The project produces a quarterly newspaper in Spanish to distribute to countries involved or interested in the project.

The following reports of the first year of activities were presented by each country at the POSCAL seminar in March 1996.

Venezuela

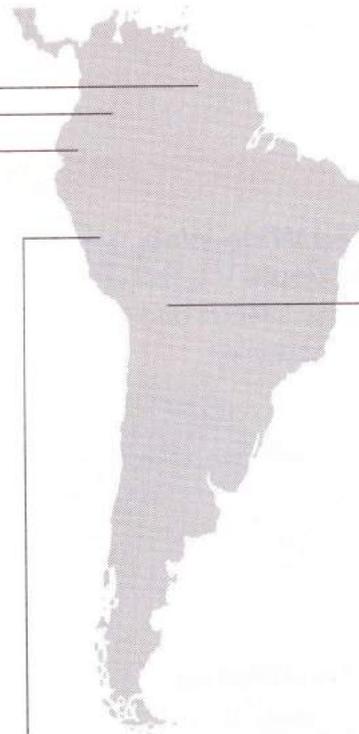
The second POSCAL Seminar took place in Caracas. This led to the creation of the National Deafblind Organization, called ORVES, which has 35 deafblind members.

Colombia

In February the first National Assembly of Deafblind People took place with 22 participants. During this they changed some of the statutes of the Deafblind Association, SURCOE, which had been created six months earlier with five deafblind people. In Colombia they are aware of 41 deafblind adults.

Ecuador

Television and radio coverage about POSCAL and deafblindness led to the identification of 30 deafblind people (children and adults).



Bolivia

The POSCAL team has contacted organisations for the deaf and for the blind throughout the country and has spread information about POSCAL and deafblindness.

There are 40 deafblind people (children and adults) in contact with the team.

What's next ...

- A training seminar for the POSCAL deafblind leaders in Peru, at the end of 1996.
- Colombia has asked to be the host of the next Helen Keller Conference, in September 1997. This will be a marvellous opportunity for deafblind people in Latin America.
- The third POSCAL Seminar will be developed in connection with the World Conference, in Colombia. We are planning to invite more countries from the region to participate in it.

Peru

POSCAL organised the First National Deafblind meeting with 18 adults, in February 1996. They had identified 31 deafblind people (children and adults).

Pioneering Course in Western Australia

A facilitator/guide course is being pioneered at the Tertiary and Further Education College in Western Australia. It has been adapted from the Touch & Go programme by CACDP in Britain and uses a range of literature mediums, such as videos and audio-cassettes, to teach tactile finger-spelling. The course covers

deafblind awareness, types and causes of deafblindness, guiding techniques and communication methods. The ten week course, which started in October 1995, has 14 students, all of whom have had experience with people who are deafblind, or who have sensory impairments themselves. Sharon Barrey

Grassick, Co-ordinator of Services at the WA Deafblind Association, says, "We certainly hope to see this course offered again and there is already a waiting list for its repeat. As it is such an innovative course, we are hopeful that it will receive some media coverage".

International Partners' Meeting of Organisations Working Internationally in the field of Deafblindness

Portugal: 12th - 13th January 1996

Representatives of 12 organisations from around the world met at this first International Partners' meeting, organised by Sense International, to discuss each others' work and consider areas of co-operation.

With an increasing number of organisations active internationally in the deafblind field the idea of a "partners' meeting" had first been discussed a year ago. The aims of the meeting were to:

- discuss the issues that are relevant when developing programmes in this field in other countries.
- analyse the situation for deafblind people in all the regions of the world.
- increase overall knowledge of the global situation.
- increase co-operation between the INGOs.
- identify areas of great need.
- identify the future plans of the International Non-Governmental Organisations (INGOs).

A lengthy discussion of the issues relevant when developing programmes in other countries was followed by an analysis of the situation for deafblind people in all the regions and countries of the world.

Issues discussed included:

- The changing nature of the deafblind population. In the North "deafblind" can now refer to people with a whole range of disabilities. In the South we very often do not know what, or where, the population is so an analysis of its changing nature is not possible.
- Community Based Rehabilitation programmes and their appropriateness for deafblind people. It was generally felt that it

is absolutely vital, if they are to work, for CBR workers to receive training in working with deafblind people and have someone overseeing the work of a number of them in this area. CBR should be seen as an essential part of an array of services but without specialist centres and training programmes there will not be any major benefits. The extent of the use of CBR is totally dependent on the situation in the country.

- The lack of services for adults in many countries. Concern was raised that many services in many countries do not consider adults. While aiming to respond to the needs and requirements of local partners INGOs also have a responsibility to encourage

partners to think about what will happen to children in their services when they become adults.

- Medical views versus education / rehabilitation approaches. It is very important that organisations whose aim is to work with deafblind people by developing education and rehabilitation programmes challenge the medical argument in favour of putting all resources towards prevention. INGOs with different aims should work together, and with local partners, to ensure that programmes overall include elements of education, rehabilitation, awareness campaigning and prevention.

It was felt that at some stage it would be a good idea to bring together some of the professionals used by the INGOs in overseas training activities. In addition to the opportunity this would give international trainers to share experiences and ideas this could lead to the production of an information pack for people delivering training in other countries. Such a pack could include orientation to the culture, attitudes towards disability and those who work with disabled people, recommendations of subjects to include in basic courses, and suggestions about how to deliver training in different countries and cultures.

It was agreed that the meeting should be repeated again at an appropriate time in the future. In the meantime summary sheets of who is working where will be regularly updated and circulated by Sense International, and smaller partner meetings will be arranged to follow larger events.

If you are interested in receiving one of the summary sheets indicating which organisations are working in which countries please contact:

Richard Hawkes
Sense International

The 12 organisations represented at the meeting were:

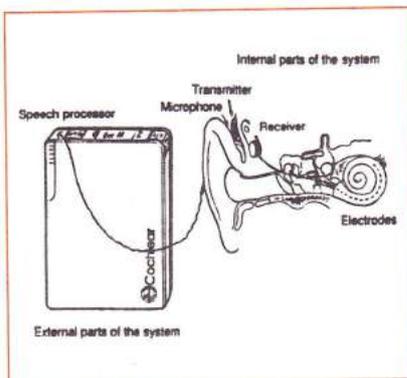
Casa Pia (Hosts - Portugal)
CESSA Larnay (France)
Christoffel-Blindenmission (Germany)
Federation of the Swedish Deafblind (Sweden)
Hilton / Perkins Program (USA)
International Association for the Education of Deafblind People (IAEDB)
International Council for the Education of Visually Impaired People (ICEVI)
Instituut voor Doven (Netherlands)
Lega del Filo d'Oro (Italy),
NUD (Denmark)
ONCE (Spain)
RNIB (United Kingdom)
Sense International (United Kingdom)
Sightsavers (United Kingdom)

Conference at the NUD on Cochlear Implant

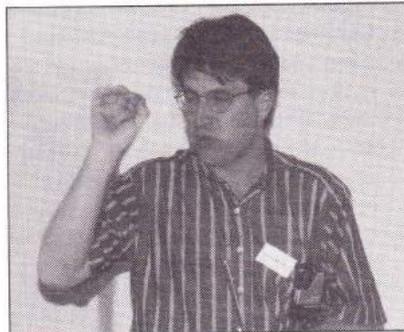
During the past 10 years new technology has developed the Cochlear Implant (CI) and changed the traditional picture of habilitation for deaf people. A conference in September 1995 tried to answer some questions around CI in children, viewed in a deafblind perspective. Claes Möller, an audiologist from Sweden, reports on the discussion this conference stimulated.

People have many questions about CI. There is a certain scepticism as to what effect CI can have on deafness and deaf culture. There are lots of misunderstandings and a lack of knowledge. CI was initially implanted in people with acquired deafness, but after a few years was also implanted in children with congenital deafness with the hope of giving them sound and hearing abilities. The development was rapid and it is estimated that around 15,000 people have received implants.

The implant gives electric stimulation, sufficiently powerful and differentiated, to the nerve ending of the hearing nerve, which in most cases is intact in subjects who are deaf or severely hard of hearing. The idea is to give different impulses for different sounds and to teach the hearing nerve and the brain to make sound perception possible, to understand speech and to facilitate speech production.



During the conference in September, most time was spent on the experiences and results of CI in children and the habilitation of children. Habilitation programmes exist and are being developed to give children better conditions for developing communication and language. In the Nordic countries, this habilitation will include both sign language and spoken language.



The impact of CI on deafblind children was discussed at the conference. There was little experience to share, and the few implants which have been given children were to those with Usher syndrome, Type I. The results so far show that these children have the same benefit of the CI as deaf children without vision problems. We have no long-term results to refer to yet, for instance, of CI in subjects who have lost their vision completely and are depending on tactile communication. We will have to wait some time, as most of the subjects who have CI are very young. Although CI in congenitally deafblind and multi-handicapped children was also discussed, information on this has not yet been compiled in a systematic way.

While the conference produced answers to many questions, others remained unanswered, such as: What happens to the emotional development of such a child? How well can spoken language be understood and spoken? Will children lose their deaf identity? What will the future look like?

There are many aspects to be covered when discussing CI. The main questions raised during the conference were: How does the interaction between the inner ear and the brain work? What is a cochlear implant? How does a cochlear implant work? How is a CI insertion done? What are the

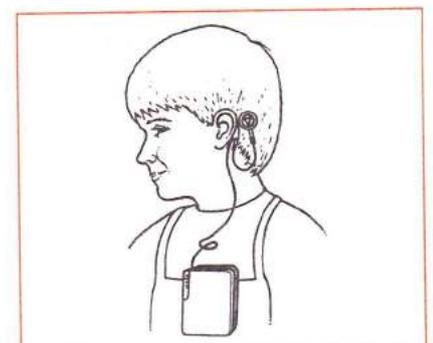
procedures for habilitation with CI? What are the results so far and how have they been measured? Can we imagine a future where all deafblind persons have CI?

Hans Borchgrevink, a neuro-physiologist from Norway, presented the different sensory organs and their development and plasticity. The hypothesis was made that the auditory centre of the brain as well as the visual centre and other parts need very early stimulation to develop. It is vital that this stimulation occurs before years 3 - 4.

Goran Bredberg, who has performed most CI surgeries in Sweden, explained the procedure. Susan Archbold, a teacher of the deaf from Nottingham, who is responsible for the coordination of habilitation services for children with CI in England, introduced the delegates to the methods of habilitation.

A personal account was provided by Irmeli Aarnio from Sweden, who has acquired deafblindness, and told the conference about her experiences before and after the implant.

This conference was the opening of a debate which should continue at other meetings and stimulate new debate. Cochlear Implants will remain, whether considered positive or negative. We need to learn more about them, and the habilitation process, to be able to help our friends with hearing and vision impairments.



The Internet, The World Wide Web and Deafblind People

Hugh Sasse is visually impaired, and became interested in Deafness and Deafblindness after changes in attitude towards him when he started using a cane. He felt that he was probably equally clumsy in his well-intentioned approaches to Deaf people, and therefore sought out someone to teach him British Sign Language. He is now in the second year of Stage II BSL, thanks to the hardwork and patience of Evan Roberts, his tutor.

by Hugh Sasse

There is a lot of talk these days about the information superhighway, Internet and World Wide Web. Some see them as the best thing since sliced bread, others say they are far too technical, and only for people who are more interested in computers than in other people. So what is the truth of the matter, and why should deafblind people be interested in it?

The internet is a collection of computers, connected together so they can communicate information to each other. That information may be pages of text, programs, or mail messages between individual people. This means it has all the benefits and all the drawbacks of people getting together. Take, for example, electronic mail. When you receive electronic mail you only see the words someone has written. You don't know what they look like, sometimes you don't know if they are a man or woman, and you don't know if they wrote it with a computer that uses large print, Braille or even a single switch like Stephen Hawking uses. So this means that people are not put off by a person's disability and they can get to know the person before they find out. This means that you can get to know a lot of interesting people fairly easily. However, people are starting to get junk electronic mail and even a few chain letters, though efforts are being made to stop this.

Another good thing about electronic mail is that it can be delivered very fast, sometimes in less

than 30 seconds, but because it is mail it doesn't interrupt you like the telephone. This means you can have a conversation with someone which is more like chatting than a postal correspondence would be, but you take things at your own pace.

There are mailing lists which you can join, so people who share a common interest can get together and talk about their interests and problems. You send your message to a computer which then sends it out to all the people on the list; they can reply to you privately or to the whole group.

The Internet has all the benefits and all the drawbacks of people getting together

There are lists about almost everything from games, cars, computers and TV programmes to beer, food and politics. There is also a list for deafblind people to get together and pass information, experiences, frustrations and good humour back and forth, and it is friendlier than many groups are. It is open to anyone who is deafblind or who is related to deafblind people, or who works with them or just cares about things that affect deafblind people. We have discussed mobility problems, communication problems, the different canes people use around the world, things that can go wrong when you are with a guide/interpreter (for example, they write out the cheque for a deafblind person, and sign it themselves! Or sign to a blind person and speak to a deaf person, and other such things that show it is going to be one of those days!). We have discussed the different alerting devices you can get, what things people use to communicate with their computer, and a collection of airport horror stories.

The World Wide Web, often referred to as WWW, is a collection of documents on different computers all over the world. These documents refer to each other in a similar way to entries in an encyclopaedia, but instead of saying

The European Deafblind Network has a mailing list in English available to all. It is called EDBNMB-L. To subscribe send an email to listserv@tp44.bad.se and in the body of the mail write SUB EDBNMB-L. That's all! Your name will be added to the list and you will receive a receipt. The next text that is entered, and all others will be sent to you.

"See also..." the relevant words are highlighted in some way. They may show up in a different colour, in bolder text, or your cursor on your braille display may move to the next such word when you press a key. These references are called links, and if you choose such a link by pressing a key on your computer the document it points to (which can be anywhere in the world) is called up, so you can travel along the links and explore. However this can take some time, and you may not find what you want. (Someone described the WWW as like a library which had been vandalised, with all the pages of the books all over the floor; the information was still there but hard to find.) This task has been made easier by programs that call up the documents and follow the links in them, and index the pages. There are a number of such "search engines" which people can query to find the WWW pages they may be interested in.

There are plans to put the Perkins School, Boston, USA library material on the internet and world wide web. This is the largest library of articles and books in the world on visual impairment, a large number of which relate to deafblindness. This will mean that Perkins information is much more flexible, allowing complex searches to be made and reporting to be tailored to individual needs.

A Special Education Course on deafblind Education is available on the world wide web from Great Lakes Area Regional Centre for Deafblind Education. An introductory course has just begun. It is intended to offer a full online college course in the Autumn. For further information e-mail: mark@ssco.esu.k12.oh.us.

Using these I have been able to find a certain amount of information relevant to deafblind people.

I have built up a deafblindness WWW resource that has links to various pages around the world describing such things as a robotic fingerspelling hand, which allows a deafblind person to read the output of a computer in American (one-handed) fingerspelling, a synthetic tadoma system which simulates the lip motion and breath patterns and throat vibrations of speech so a deafblind person can read them, and details about Usher syndrome. There is a small section where I link to pages about conferences on deafblindness. I have a list of periodicals people can obtain, including Deafblind Education, a growing list of equipment, and a bibliography. I have started work on a list of service providers around the world, although this has huge gaps in it at present. I would be grateful for any further information that would make this resource more useful. I should add that this site is extremely unofficial, and in no way represents the opinions of the university where it is situated. I have tried to minimise the space it takes up so there will not be demands to remove it, but unfortunately that could happen, as it is not relevant to the work of the research group.

There is a way to access the WWW by electronic mail that does not give access to the search mechanisms. This, and WWW access by telnet (connecting to a machine and logging in on a special account) are mentioned on my deafblindness page.

It is difficult in an international publication such as this to describe how to get started on the internet. You need a computer of some sort and a modem, or an account on a computer already connected (such as at a university). If your machine is not already connected you will need a connection from an "internet service

provider", who will charge you depending on how much you want from them. For example, you may want to create your own WWW page or have one made for you. In the UK there are many different providers, and it is fairly hard to choose between

them. Although there are a lot of books on the topic, I am unable to say which are in Braille or Moon, but I gather the number is increasing and I have heard there are some being produced on disk. The internet resources I have referred to are:

1 The DEAFBLND list:

Send a message to

listserv@tr.wosc.osshe.edu

with a message body of

SUB DEAFBLND <your full name>

If you send the message

INFO REFCARD

to the listserv you can find out about the digest mode and other features. The address of the list itself is

deafblind@tr.wosc.osshe.edu

so that is where messages for all the people on the list should be sent.

2 A Deafblindness WWW resource

This is at:

<http://www.image.dmu.ac.uk/deafblind/WWW>

send a message body of help to

agora@www.eng.dmu.ac.uk

and this will describe how to use the system. You will be restricted to how many requests you can make per fortnight, depending on your location, but you can get round this by running the software locally, which will improve the response time and reduce the load on our system.

Other resources by electronic mail

Send an empty message to

DrBob@mailback.com

to get more information about other services you can get by electronic mail. The message you will receive is about 65kB. I can be reached by electronic mail at

hgs@dmu.ac.uk

CONFERENCE
NOTICE

Interpreter Training

**Second European Workshop
26th - 30th October 1996, Shrewsbury, England**

The workshop will serve as a follow-up to the work initiated at the Lisbon meeting, and will examine the curriculum and organisation of interpreter services at an international level. We hope that many of the participants from the last workshop will be able to attend again and welcome their suggestions for the programme.

The workshop will be hosted by the Royal National Institute for the Blind at the scenic location of Conover Hall School in Shrewsbury. The nearest airport is Birmingham International. Accommodation and transport costs from the airport will be met by the Helios grant agreed by the European Deafblind Network. Transport to Birmingham must be met by the participants. Places are limited to 35 participants.

For further details and programme suggestions, please contact:

William Green, Committee Chairperson, Lega del filo d'oro, via Montecerno, 1 - 60027 Osimo (AN), Italy

(Tel: + 71 72 45 1) (Fax: + 71 71 02)

Conditions and Syndromes that can Result in Deafblindness

In the second of our series examining prenatal causes of deafblindness, this edition focuses on CHARGE Association.

By David Brown, February 1996

Identifying Characteristics

CHARGE Association is a multi-featured disorder characterised by a unique combination of diverse abnormalities. The pattern of features was first described in 1979¹ but the acronym 'CHARGE' was first used in 1981.² This is, therefore, a relatively newly-recognised condition. The acronym 'CHARGE' is used to describe a heterogeneous group of children who exhibit at least four of the features prefixed by the letters of the acronym and including one or other of choanal atresia and colobomata. The combination of critical features was identified as:

- C Coloboma** are ocular deformities involving an absence of part of the eye, and visual impairments may or may not be present. Coloboma of the iris may reduce the child's ability to adjust to bright light; coloboma of the retina will create a blank area in the child's visual field. Anophthalmos or microphthalmia may also be present.
- H Heart defects** include tetralogy of Fallot, patent ductus arteriosus, atrial and ventricular septal defects, and others.
- A Choanal Atresia** a narrowing or a blockage of the passages between the nasal cavity and the nasopharynx, is one of the major criteria for diagnosis. The blockage may be unilateral or bilateral, membranous or bony.
- R Retarded growth** may become manifest as the child matures. The majority of children with CHARGE Association are below the third percentile of physical growth norms.

G Genitalia anomalies. The incomplete development or under-development of the external genitals is common in males, very rarely evidenced in females.

E Ear anomalies can affect the external ear (lop or cup shaped, large, small or absent), middle ear (ossicular malformations, chronic serous otitis, stapedius tendon anomalies), and/or the internal ear (especially high frequency sensori-neural hearing loss). Mixed hearing loss (ie conductive loss with sensori-neural loss) is the most common form of hearing loss in CHARGE Association. Malformation or absence of the semi-circular canals is fairly common.

Evidence exists of other anomalies associated with this condition in addition to those above:

- abnormal tongue size
- cleft lip and/or palate
- facial palsy
- renal abnormalities
- malformations of the larynx
- atresia of the oesophagus with - tracheosophageal fistula
- skeletal abnormalities

Historically, the medical profession considered mental retardation a characteristic feature of CHARGE Association. Recent literature suggests this may now be coming to be seen as an outcome of the other combined anomalies rather than as an integral anomaly of the Association itself.^{3,4}

At the First International CHARGE Association Conference (St Louis, 1993) it was proposed to alter the criteria for diagnosis to make earlier

assessment easier by incorporating features which can be identified soon after birth, but this proposal has not yet been pursued.

Aetiology

The exact cause of CHARGE Association is still unknown but research suggests a variety of catalysts may induce the irregularities present in the CHARGE sequence of anomalies. The majority of cases are thought to be sporadic with no obvious evidence of genetic involvement. There is some evidence in the literature of characteristics of CHARGE being inherited, and also some evidence to suggest chromosome deletion in some cases.⁵ References in the literature, and many parents of children affected, suggest the possibility of linking CHARGE with exposure to teratogens (substances which interfere with normal prenatal development) contained in pesticides, fungicides and wood preservatives, in the early stages of pregnancy, but this has not been proven. It seems likely that multiple genetic and environmental factors play a role in the aetiology of the CHARGE Association.

Prevalence

In 1993 Hall referred to over six hundred children world-wide having been identified as presenting with CHARGE Association.⁶ The support group in the United Kingdom has recorded over one hundred people with CHARGE, of whom several have died.⁷ A survey of the deafblind population in New England aged nought to fifteen in 1992 revealed four percent with the diagnosis of CHARGE Association;⁸ CHARGE accounts for six percent of the nought to five year old population

currently being worked with by the Sense Family Centre in London.

Educational Implications

Most of the literature on CHARGE is medical and until five or six years ago showed little understanding of the educational needs or potential for development of children with CHARGE Association. This has improved in more recent literature and, as explained above, with growing awareness of the importance of early educational intervention and of the need for appropriate educational approaches, it should become increasingly rare for 'mental retardation' to be automatically ascribed to young children with CHARGE Association.

It should become increasingly rare for 'mental retardation' to be automatically ascribed to young children with CHARGE Association

Severe health problems are common in the early lives of children with CHARGE Association, usually necessitating multiple surgeries and repeated and prolonged hospitalisation.⁹ It may be difficult for therapists and educationalists to gain access to children and their families during this period, but such access should be facilitated in a planned and co-ordinated manner as early as possible, not just to ensure optimal development for the child but also to try to minimise the devastating impact of these repeated surgeries and hospitalisations.

As with all young children born with multiple disabilities, it may take years to determine fully the extent and nature of each disability. The present writer has worked with several young children with CHARGE Association who presented as having severe visual impairment and severe hearing loss but who, subsequently, made excellent use of residual vision and hearing after appropriate early intervention and a great deal of hard work by their families and local teachers.¹⁰ A survey of thirty-nine children carried out in the United Kingdom in 1992 revealed that all had been delayed in their early motor development (mean age of walking was four years) yet one third had not received input from a physiotherapist. Similarly, of the children with functional visual impairment two-thirds had received no input from an advisory teacher for the visually impaired in the pre-school years, and of those with dual sensory

impairment only just over a quarter had received input from a 'deafblind' specialist in this crucial period.¹¹ As CHARGE Association becomes better known in the deafblind field it is hoped that this situation improves.

International Aspects

The two International CHARGE Association Conferences (St Louis 1993, Portland 1995) were organised by CHARGE Accounts, Quota Club, (2004 Parkade Boulevard, Columbia, MO 65202, USA). The Third Conference is planned for Boston in July 1997.

The First Australian CHARGE Association Conference took place in Sydney in 1994, organised by the Royal New South Wales Institution for Deaf and Blind Children, (36-365 North Rocks Road, North Rocks, New South Wales, 2151 Australia). The Second Australian Conference is planned for North Rocks in July 1996.

In the United Kingdom the key organisation is the CHARGE Association Family Support Group run by Mrs Sheila Draper, (115 Boundary Road, Colliers Wood, London SW19 2DE, England). The annual CHARGE Association Picnic will take place in London on 4 August 1996, and it is hoped to feature presentations and a meeting about CHARGE Association at the Sense Weekend Away in Birmingham in September 1996. The present writer has contacts who are interested in CHARGE Association in Canada, Italy, Denmark, Sweden, Norway and Germany.

References

- 1 Hall, BD (1979). "Choanal Atresia and Association Multiple Anomalies" *Journal of Paediatrics* **95** 395-398
- 2 Pagon RA, Graham JM, Zonana J and Youing SL (1981). "Congenital Heart Disease and Choanal Atresia with Multiple Anomalies" *Journal of Paediatrics* **99** 223-227.
- 3 Blake KD and Brown D (1993). "CHARGE Association Looking at the Future - the Voice of a Family Support Group" *Child: Care, Health and Development* **19** 395-409.
- 4 Blake D, Russell-Eggitt IM, Morgan DW, Ratcliffe JM and Wyse RKH (1990). "Who's in CHARGE? Multi-Disciplinary Management of Patients with CHARGE Association" *Archives of Diseases in Childhood* **65** 217-223.
- 5 Blake et al (1990). 220
- 6 Hall, BD (1993). "What's in a Name? History of CHARGE, Recognising and Naming Syndromes" *Paper presented at the First International CHARGE Syndrome Conference, St Louis, Missouri.*
- 7 CHARGE Association Family Support Group. Mr & Mrs N Draper, 115 Boundary road, Colliers Wood, London SW19 2DE, United Kingdom. (tel: 0181-540 2141).
- 8 Riggio, M (1992). "A Changing Population of Children and Youth with Deafblindness" *Proceedings of the National Conference on Deafblindness: Washington DC, 20-26.*
- 9 Blake et al (1990).
- 10 See also Riggio (1992). 23.
- 11 Blake et al (1993).

Developing services in Uganda

Inger Rodbrøe, a consultant on deafblind services from Sweden, visited Uganda in October, 1995, to build on staff training begun during her first visit in 1994 and to prepare individual programmes for children at the Buckley High School, Iganga. She reports here on her experiences during her stay.

The deafblind unit at the Buckley High School has two classrooms with capacity for 10 deafblind children. I feel resources for deafblind services in Uganda should focus on the services this School has begun in order to build up expertise on deafblindness in the country. The teachers at the School should, in the future, be able to assess deafblind children and support parents with young children. They could also support new deafblind units at other schools where provisions for blind or deaf children already exist.

Organising the unit's daily work

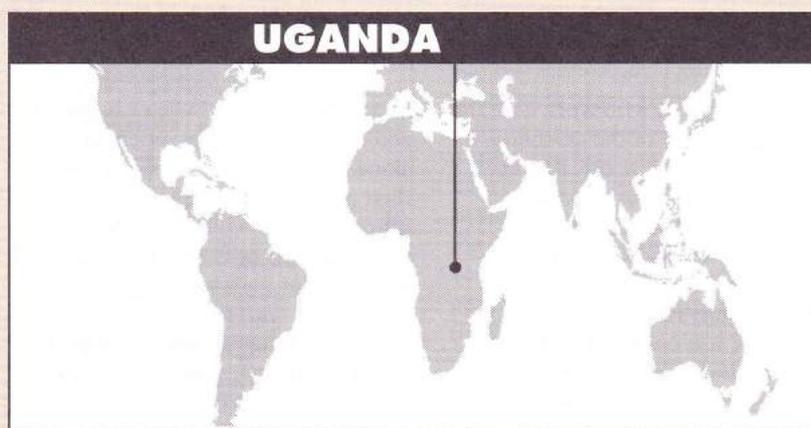
We arranged the two rooms at the School in different ways: One supported play and motor activities, and the other was divided into private areas, where more 'formal teaching' took place. As part of a working model for the unit we allocated each child a main teacher who was responsible for:

- their individual programme,
- passing information to other teachers and the house-mother,
- making individual materials,
- supervising other teachers and the house-mother on the child's programme.

Each child is to be evaluated every fortnight by the five teachers, house-mother, head of the unit, and the child's main teacher, who will also take notes of the discussion. A daily programme was established of personal tuition in the morning, followed by group activities such as play, music, handicraft, or cooking in the afternoon.

Staff training

The staff training at the unit was very practical, involving participation in



assessing the children and making individual plans together. During this questions were raised, such as:

- was the child deafblind?
- what were their potentials?
- what kind of programme would they need in the future?

After designing an individual's programme I would work with the child under the observation of the teachers. The child's main teacher would then work with the child under my supervision. The next day the other teachers worked with the child under the supervision of the main teacher, and so on. The house-mother also took part in the sessions. This method proved efficient and valuable in raising fresh ideas.

In the afternoons we would reflect on the activities of the day, discuss theoretical and practical topics, and practice different forms of communication.

The team of five teachers worked well together and were very devoted to their work. They were eager to learn and several are gaining further qualifications in special education. The head of the unit is responsible for the management, staff supervision and assessment of new children.

Future work in Uganda

During my two visits to Uganda I have become informed about the services for deafblind children, and would like to make suggestions for building on the work already taking place. Firstly, a follow-up of the staff training begun at the Buckley High School would be invaluable for the teachers. Secondly, a workshop for pre-school deafblind children, their parents and other professionals would help these groups to work together, share experiences and generate new ideas. Siblings could be invited to participate as helpers and to promote their understanding. Also, week-long workshops could be held for deafblind children and professionals from Kenya and Tanzania, covering assessment and communication. Participants could then go on to become the future supervisors of deafblind units in East Africa.

Inger Rodbrøe is a consultant at the Federation of the Swedish Deafblind, and Swedish Handicap International Aid.

Some Aspects of Rehabilitation

by Ann Svensson

Ann is a consultant for deafblind adults, at the National Swedish Agency for Special Education, which provides support and services to handicapped children and adults, their families, teachers and service-staff. She specialises in co-ordinating rehabilitation services for adults with acquired deafblindness.

For those of us who work with the rehabilitation of the deafblind, it is important to realise that each individual exists within a social context. The deafblind are rarely completely alone and nearly always have contact with people from different groups surrounding them. Despite this, it is common for the primary interest and work of the professional to be directed toward the deafblind individual only, leaving the family or others in close contact with him outside the rehabilitation process.

In an earlier study of the relationship between society's rehabilitation efforts and the quality of life experienced by the deafblind, I used a model for measuring quality of life, developed by Madis Kajandi, a Swedish researcher and psychologist. His definition of this concept states that:

"... a person has a higher quality of life when he has improved:

- *external living conditions,*
- *interpersonal relationships,*
- *inner psychological condition".*

(Kajandi, 1981)

Every person I interviewed in that study agreed that the area in which their quality of life was lowest was interpersonal relationships. This perception has been confirmed time after time through conversations I have had with other deafblind individuals. For some of the deafblind, it is more important that their family understands what their handicap involves, rather than they receive the best practical help. Dysfunctional relationships are often a major stress factor for the deafblind and can result in their rehabilitation process being hindered.

The Social Environment

Deafblind individuals' social environments can differ greatly. Some

have a family with a wife or husband and/or children, while others live alone. Some have close contact with their parents, brothers and sisters, and other relatives, while some no longer have any contact at all. The closest relationships for some deafblind persons are with friends, other members of their deafblind support group, work colleagues or neighbours. A few only have contact with rehabilitation personnel or volunteers, who become very important people in their life.

In the remainder of this report, I will focus on relationships within the family, though the theories presented are also applicable to other groups of people which may surround the person. The degree of closeness experienced in relationships can, of course, vary widely. Even if there is a physical and geographical closeness, as in the case of a husband and wife who share their lives and housing arrangements, there can be a lack of emotional, mental or communicative closeness between them.

The Family as a Social System

A general system theory can, by and large, be applied to the family. The concept of a comprehensive perspective is fundamental to this theory. The family must be considered as a unit in which all members have mutual relationships with each other. Each person affects, and is affected by, the other individuals within the family. If one member in the system suffers from a problem such as an illness or handicap, there are consequences for the entire system. Deafblindness, for example, is not only an individual problem, but greatly influences the surrounding family. Family members often experience similar reactions to a

crisis as the affected person himself.

The family system is characterised by a relatively high level of stability, and there exists a natural force which seeks to achieve balance: family-homeostasis. When stability is threatened by a new element, such as the handicap of a family member, the other members react in an attempt to restore the balance. The system displays a reluctance to change but is, in fact, constantly in the process of change and development. If changes are too sudden or difficult to handle, it is not always possible for these to be managed by the family.

Family members often experience similar reactions to a crisis as the affected person

Outside help may be required. It is important to note that, in the case of deafblindness, there is often an inherent process of change over time, since the degree of sight-and hearing-impairment deteriorates progressively (Lundsbye et. al., 1991).

The Family and the Professionals

Karl Gustav Piltz and Kristin Gustavsdottir are psychotherapists who have worked in Sweden with the problems existing in relationships between the family and social service professionals. In their book, *Den Osynliga Familjen* (The Invisible Family, 1992), they discuss the importance of involving people surrounding the impaired individual in

the rehabilitation process. They describe how inadequate contact between the family and the professional network can be identified:

- interest is focused primarily upon the patient, not the family members,
- insight into and understanding of the family members' situation is limited,
- the family is not viewed as a resource,
- there is no clear role for family members in their relationship to social services,
- dialogue is inadequate between the agencies and the family,
- the family is not kept informed about plans for the handicapped individual's rehabilitation,
- family members do not see themselves as active agents in the rehabilitation process, and consequently accept a peripheral, often insignificant, role.

Piltz and Gustavsdottir also describe how people surrounding the patient feel invisible to the professional staff. They experience an unwelcome attitude, and feel unsure in their contacts with the experts, not knowing precisely how they should interact with them. Furthermore, they do not understand how they can best relate to the handicapped family member, or what demands are being made of him during the period of rehabilitation. The family members are also unsure how responsibility should be divided between them and the professional staff. This often leaves them feeling helpless in their efforts to influence what happens during the rehabilitation process. Many state that they do not sense an understanding of their own situation. Despite the fact that they may find themselves in the middle of a difficult crisis, they feel they are expected to behave as if they are totally unaffected by the circumstances surrounding them. They sense their questions and feelings of worry and anxiety are not acknowledged by the professional staff.

Unfortunately the impaired person is not always conscious of the difficult situation experienced by his family members. His own problems loom so overwhelming in his life that he seldom has the ability to see those difficulties affecting others. Such an analysis can give rise to a possible misunderstanding. Obviously, the focus of our work in the rehabilitation process must

be upon the deafblind individual. But in order to achieve the desired results, it is necessary to acknowledge the importance of the contributions which can be made by family members and other people surrounding him. This wider focus is not only vital for the social and psychological rehabilitation providers. Other participants in the rehabilitation process must make attempts for greater co-operation with the family by giving them opportunities to be involved, via ADL-training, mobility-training, and learning alternative communication methods.

For some deafblind people it is more important that their family understands what their handicap involves, rather than they receive the best practical help

Changes on Many Levels

When an individual has a sight or hearing impairment, his daily existence is affected in many different ways. Those areas which are traditionally classified as problem areas for the deafblind, such as information acquisition, orientation and communication, are only a few of the components in the entire situation. Aside from the fact that the deafblind person and people around him may experience a variety of reactions to the larger crisis, life is suddenly dominated by a whole host of questions and problems which they had never previously encountered. The adjustment process involves many challenges and decisions, and adapting to both the present circumstances and the future uncertainties adds stress to the lives of all concerned. The balance within the family structure, for example, can be dramatically affected, with the stronger members becoming weaker and vice versa.

Family Reaction Patterns

In my work with deafblind individuals

and their families, I have discovered a great need for knowledge and a personal sense of involvement. I have also witnessed a wide variety of ways in which family members handle the problems they face with the handicapped person, and different strategies they use in attempting to overcome the situation. These responses and strategies are very similar to defence mechanisms described in classic psychology literature: repression, reaction, isolation, avoidance, denial, regression, identification and projection.

Defence mechanisms are vital self-preservation functions which the individual is unconscious of. They are as important for one's psychological survival as the body's immune system is for one's physical survival. As such, they should be considered as entirely normal and necessary phenomena which perform the task of moderating anxiety arising from conflicts within the individual and between him and his surroundings. In this way, his personality can be held in balance (Cullberg, 1988).

However, with regard to deafblind individuals and their family, I have noticed that the reactions of family members may differ. The degree and category of handicap is often quite unrelated to the nature of the reaction. While some family members have difficulty dealing with a relatively minor sight or hearing impairment, others become very involved in the life of the handicapped person despite the fact that their impairments may be severe and multiple.

Some common reactions are:

Denial: One or more members refuse to see or admit the problem, and demand that the deafblind person should function as normal.

Dissociation: A similar reaction, but with a stronger and deeper tone which may result in the family member not only refusing to admit the existence of the handicap and accompanying problems, but refusing to personally associate with the deaf blind individual himself.

Over-protection: The family member becomes unnecessarily anxious, and sometimes domineering or controlling, in his attitude toward the deafblind person. He often speaks on the person's behalf and makes decisions which affect him. This can create a dependent relationship, removing from the deafblind person his sense of personal responsibility and undermining his independence.

Dependency: The family member may not be able to adapt to the changing circumstances or accept increased responsibility in the new situation, reacting instead by becoming weak in relation to the handicapped person.

Subordination: Similar to dependency, but going one step further in that the family member appears to give up his own life, his own ambitions and interests. He may only participate in leisure activities which are designed for the deafblind family member, and only meet socially with people in the deafblind support group.

Competition: For every problem afflicting the deafblind individual, the family member suffers something even worse in the form of sickness, depression, etc. This is often a clear signal that the family member's own crisis and deteriorated situation has not been sufficiently noticed or addressed. Such a reaction must be dealt with effectively, since the deafblind person has little chance of obtaining appropriate rehabilitation under such circumstances.

If there are children in the family, their reactions are somewhat different. The most common strategies which they use, according to my observation, are:

Responsibility: The child becomes the parent, taking upon himself (or being forced to accept) a level of responsibility which is too great. This is often coupled with guilt feelings such as, maybe it is my fault that Mummy has become blind. A tragic situation and pattern develops when parents do not take notice of this and permit the child to be guide, interpreter and spokesperson.

Shame: Deafblindness is a handicap which is sometimes not noticeable, but which can also be very obvious. The child may experience feelings that his parent is odd and different. He may react by isolating himself, sitting alone at home, never inviting friends to come home, refusing to go out in public with his handicapped parent, and lying about the reality of his family life.

These strategies are similar to those used by children of alcoholics in order to cope with reality (Bengtsson, Gavellin, 1994). There is, however, a major difference: in families where a parent is handicapped, the child's attitude toward his parent can change to something much more positive if someone simply notices the situation and takes time to help the child understand what the handicap

involves. They are relieved when they realise it is not Mummy's or Daddy's fault that they trip over the sidewalk, walk into a lamp-post, speak unclearly or cannot hear. I have seen situations where children, after learning about the nature of deafblindness, came to see themselves and their family as special and actually quite interesting, often eager to show off their parent in front of their friends.

Children can also carry an unspoken fear that the handicap is hereditary and that they themselves will become like their parent. This question should always be addressed by a competent professional, such as a doctor who specialises in genetics. If the parent has Usher, for example, then there is the possibility that one or more of the children has inherited it.

It is sometimes necessary to direct rehabilitative efforts towards family members

The described reactions and strategies may or may not be conscious, but are seldom well thought out. The family or others surrounding the deafblind of course need not necessarily use these methods or exhibit these reactions. Many do respond in a positive and constructive way, serving as a valuable resource for the deafblind individual and helping to optimise the results of the rehabilitation process. The pattern within each family is also dependent upon a variety of other factors including: personality; empathy and emotional capacity; knowledge, insight and understanding; maturity; closeness, sincerity and depth in communication; phase of life; and support from outside the family.

A review of coping-mechanism theories reveals additional methods of tackling the problem matrix. Coping may be defined as:

"...those behaviours and thoughts which are consciously used by an individual to handle and control the effects of anticipating or experiencing a stressful situation. [One may use] a three-part classification of coping: constructive, passive and escape coping. Constructive coping refers to active and constructive solutions, cognitive as well as behavioural, aimed at altering a stressful event. Passive coping refers to solutions where nothing is done to alter the

situation, or to move away from it. Further, escape coping is characterised by cognitive and behavioural strategies intended to physically or psychologically leave the field". (Hallberg, 1992)

The Family as a Resource

As we have seen, it is sometimes necessary to direct rehabilitation efforts toward family members themselves. But the family can also be involved in other ways. Their possible roles are described by Piltz and Gustavsdottir:

Advisers: The family has a tremendous knowledge of the [afflicted] member and can give vital pieces of information about his background and personal situation, which are important to consider when society prepares to step in with professional help. Most families will gladly co-operate as advisers, when they sense that their knowledge and opinions are valued and can be used for the benefit of all concerned.

Team Members: In the role of advisers, the family and the professional care providers exchange information and knowledge. Co-operation can develop further, however, when all parties agree to share the tasks and responsibilities among themselves as members of a team. The role of team members is often perceived as a positive experience for the family members, and they are usually willing to participate in this way. They receive meaningful tasks and feel that they can contribute to make the best of the situation.

Piltz and Gustavsdottir's perspective is interesting but leaves out a most important factor: the deafblind individual's integrity must never be compromised. As a cardinal rule for all rehabilitation efforts, it is essential that the deafblind person himself is always given the opportunity to personally participate as part of the team and make decisions about which methods will be used and who will be involved in the process. The family members should never be invited by the professional care providers to be active in the rehabilitation process without the deafblind person's approval and participation in the planning stages of such co-operative efforts. ■ ■

Contact: Ann Svensson, National Swedish Agency for Special Education, Erik Dahlbergsgatan 11 B, S - 411 26 Gothenburg, Sweden

Basic Services for the Elderly Deafblind: Surveys and Statistics

Ole E. Mortensen is Information Manager at the Information Center for Acquired Deafblindness in Copenhagen. Before that he was a teacher at the Department of Communication, Roskilde University. He presented the following paper on deafblind statistics at the Poitiers Conference.

This study will focus on the elderly deafblind. It will examine those who have become deafblind due to age related vision and hearing impairments. Although this is by far the biggest group within the deafblind population, it is a group that has been largely ignored in most countries until now. This has resulted in many people not receiving the help, support and assistance that they need.

In order to offer services to the elderly deafblind we need to know things, such as:

- the number of people we are talking about,
- more about their situation, problems they experience, and their needs and wishes,
- whether the existing services are useful and sufficient, and, if not, convince decision makers that services should be improved and extended,
- identify the elderly deafblind and offer support services.

The first step of this plan is to get an estimate of the size of the group we are talking about and to use these figures for creating awareness of this group among professionals, decision makers and the public.

Elderly people who acquire deafblindness in old age are fairly invisible in society. They live in their own homes or in institutions, where their sensory loss is not noticed, or just considered an inevitable part of growing old that must be accepted.

In some countries in Europe there is a growing awareness of this group as a result of surveys to establish the size and characteristics of their problems.

Three of these were carried out in Holland, Denmark and the UK.

Although the reports differ in the way they present their findings, distinguish between age groups, and describe the cause of deafblindness, I have identified some key points and findings. The surveys all used the same functional definition of deafblindness.

There are several differences in the methods used in the surveys and it is interesting to notice that despite these differences, the results they produced were in many ways very similar.

It should be noted that none of the studies and surveys claim to have found exact and accurate numbers. There is still a lot of estimation and even guesswork involved in many.

UK

Until the 1990s estimates of the number of elderly deafblind were based on the "Breaking Through" report of 1988. This estimated the number of deafblind people in the UK to be around 25/100,000. Sense, the National Deafblind and Rubella Association, has been involved in conducting the latest survey in the UK.

The various methods used to assess each region in the UK employed:

- questionnaires sent to all counties,
- questionnaires sent to homes/institutions, voluntary agencies and known individuals,
- seminars to raise awareness and interest for the survey,
- meetings with Health and Education Departments to agree distribution methods,
- questionnaires to social workers, health authorities, organisations

and clubs for the deaf, blind and deafblind.

These surveys produced an average number of 21,000 deafblind people of all age groups in the UK (approx. 40/100,000). Survey findings ranged from 30/100,000 to 58/100,000.

According to estimates made by Sense, approximately 14,000 (66%) of these were elderly, mostly deafblind due to age related impairments.

Holland

The known number of deafblind people in Holland was 300 (2/100,000) until the 1990s, when two large surveys were conducted. One counted all deafblind people in the country (1991), and the other focused on the elderly deafblind living in rest homes and nursing homes (1993). Both were carried out by Stichting Doof-Blinden.

In 1991 the survey "Deafblindness in the Netherlands" researched all GP's and nursing homes in the country for the numbers of deafblind individuals in their care. 6,700 letters were sent out, to which there was a response rate of around 80%. The registers of the mentally handicapped were also examined. From the responses it was estimated that there was a deafblind population of around 2,250 (a prevalence of 15/100,000) with approximately 1,600 elderly deafblind.

The second survey, "Old age deafblindness" was sent to 1,850 resting and nursing homes for their reports of deafblind inhabitants. Elderly people who live in their own homes, although a large proportion, were not counted, since the purpose of the survey was to look at the situation of deafblind elderly people in institutions.

Approximately 2,700 elderly

deafblind people were found, which enabled an estimate of 3,000 - 4,000 deafblind people in a population of 15 million to be made (a prevalence of 20/100,000 - 27/100,000).

Denmark

Denmark has 16 counties. A study was made of one of them, Aarhus, which, with a population of 600,000, contained around 11% of the Danish population. The survey was conducted by the Information Center for Acquired Deafblindness. Personal contact was made with the field workers before they were asked to report every person they knew of with a combination of vision and hearing impairments. This was followed up with an interview to determine whether the reported persons fell inside their working definition of acquired deafblindness.

118 people were identified as having acquired deafblindness. This enabled an estimate for the number of people with acquired deafblindness in Denmark to be made at 1,100 (a prevalence of 22 /100,000). If the figure of 150 congenitally deafblind is added, there is a prevalence of 25/100,000 deafblind people in the population.

What do the surveys show?

Many things. They give us a more authentic image of the groupings within the deafblind population. The percentage of elderly deafblind people within the deafblind population has been estimated at:

- 66 % in the UK
- 72 % in Denmark
- 67 % in Holland

Prevalence of age related deafblindness in the elderly population

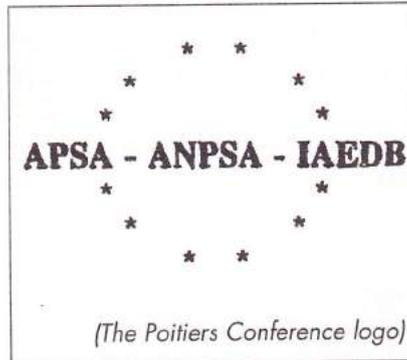
The elderly population was determined as people over 65 years.

UK - In every 100,000 persons over 65 it is estimated that 255 of them are deafblind because of old age! The Royal National Institute for the Blind have carried out a survey which shows a very high prevalence of hearing problems in visually impaired elderly people.

Holland - There are about 2 million elderly people in Holland. Of that population, around 135 in every 100,000 are deafblind and living in nursing and rest homes. The numbers from Holland on elderly deafblind are probably an under-estimate, since

many elderly people live in their own homes and were not counted.

Denmark - When looking at the causes of deafblindness we find that 82% of the people with acquired deafblindness in Denmark are deafblind because of old age. In Denmark 710,000 people are over 67 years, 900 of whom are deafblind because of old age, which gives a prevalence in the elderly population of 127/100,000



Survey Methods

The following research methods were used, and problems encountered, during the surveys:

- Studying registers of the hearing impaired, visually impaired and mentally handicapped: This requires the existence of, and access to, registers.
- Postal questionnaires to medical and care staff: Respondents must be willing and able to respond, understand the demands of the survey and able to recognise when a person is deafblind.
- Questionnaires after initial contact: This generally produces a better outcome, since there is an opportunity to clarify the questionnaire and motivate people to respond.
- Qualitative methods: This involves meeting the people who might be in contact with the deafblind.

Definitions

Doubts are often expressed over the validity of survey findings due to inconsistent definitions used by the respondents. In many surveys the feeling is expressed that the figures are probably an under-representation of the true number.

In the surveys examined, functional definitions were used, such as the following:

"A person is deafblind when she/he has a severe degree of combined visual and auditory impairment."

Some deafblind people are totally deaf and blind, while others have residual hearing and residual sight. The severity of the combined visual and auditory impairments means that deafblind people cannot automatically utilise services for people with visual impairments or with hearing impairments ... Deafblindness must therefore be regarded as a separate disability which requires special methods for coping with the functions of everyday life." (Nordic Survey)

A functional definition depends on a subjective assessment. How do you define "severe" so that everyone will have the same understanding of the word? This may be overcome by using a medical definition. Denmark applies this for assessing blindness; diagnosing blindness when vision is 6/60 or less. When using a medical definition it is much clearer who is included in the group and who is excluded.

The validity of a survey depends on respondents sharing a definition of what is being examined. The surveys mentioned here raise this question when they reveal discrepancies between areas otherwise inexplicable in demographic terms.

In addition to surveys of the number of deafblind people, there have been estimates of the number of people with a combined visual and hearing impairment. In 1991 the Royal National Institute for the Deaf in the UK estimated that there were 50,000 people with some degree of both visual and hearing impairment, (approximately 431/100,000). They also discovered that may be as many as 45% of people aged over 75 with visually impairments who also have difficulties with hearing. The Danish survey revealed similar findings, indicating a prevalence of combined visual and hearing impairment in the elderly population of 346/100,000.

Although I have discussed the findings of a range of surveys which used different methods and were conducted in different countries, it is clear that deafblindness is experienced by a substantial proportion of elderly people. While the exact prevalence can be argued, it should be agreed that we must now find ways of assisting this significant group of people who have acquired deafblindness.

Ole E. Mortensen

Ole can be contacted at the Institutionen for Dove, Generatorve, ZA, DK-2730 Herlev, Denmark.

Developments in Slovakia

1994 and 1995 were good years for people who work with the deafblind in Slovakia. Thanks to the Hilton/Perkins International Foundation, three teachers from Slovakia took part in an Educational Leadership Program at the Perkins School at Watertown from September 1994 to June 1995. This gave the teachers theoretical and practical experience.

During the study visit the three participants created a project to improve understanding of the deafblind population in Slovakia.



This had three aspects:

1 A four year course on the pedagogy of deafblind and blind multi-handicapped children at Comenius University in Bratislava. This will be studied by nine pedagogical workers from the Deafblind School in Slovakia and 18 others, who will qualify as teachers of deafblind or multi-handicapped children.

2 A survey of deafblind people in Slovakia. This will be undertaken in conjunction with the Union for the Blind in Bratislava, who will use the survey results to develop a service for deafblind adults.

3 The translation of professional material into Slovak and Czech to assist practice.

The Deafblind School has been rebuilt, with a new building opened in 1994, and a further one planned to open this year. The School currently has eight students, aged between six and 20, spread between two classes. Staff include two teachers, six daily educators, and four teaching assistants.

Janka Sarisska, Director of the Deafblind School, Slovakia

CONFERENCE NOTICE

Nordic Conference on Deafblindness

Communication, Information and Co-operation: Deafblind People's Possibilities for Communication and Autonomy in the Modern Society

28 August - 1 September 1996, Copenhagen

Every two years the Nordic Staff Training Centre for Deafblind Services organises a Nordic Conference on Deafblindness and invites deafblind people, their family members and staff to participate. The Conference this year will comprise two days of plenary and workshop sessions, covering:

- Communication and Handicap
- Tactile Sign Language Communication
- Mother-Child Communication - What is Specific for Congenitally Deafblind Children?
- Quality of Life of Deafblind People
- Communication and Cooperation between Parents and Staff.

One day will have special three hour Focus Sessions on:

- The Profile of Development of Congenitally Deafblind Persons
- Communication with Congenitally Deafblind Persons
- The Role of the Counsellors for Congenitally Deafblind People
- Congenitally Deafblind Persons Also Get Older

- Cochlear Implant
- Family Dynamics
- Communication with Persons with Acquired Deafblindness
- Deafblind Elderly People
- Electronic Communication
- Interpreting for Deafblind People
- Autonomy
- The Role of the Counsellor for People with Acquired Deafblindness

We expect to get around 200 participants from the Nordic countries, and hope the programme will have things of interest for all the participants whatever their involvement in services and support for deafblind people.

The conference languages will be the Nordic Languages. Further information from:

NUD, Slotsgade 8, DK-9330 Dronninglund, Denmark. (Tel: + 45 98 84 34 99 / Fax: + 45 98 84 34 99)

IAEDB Strategic Planning Group Report to Executive, April 1996

This group has now finished its report on the future of IAEDB. It will recommend the 12 following proposals to the Executive at its meeting in May.

Background

Following the Executive meeting in Poland in May 1995, the Association Chair, Jacques Sourieau set up a Strategic Planning Group to consider the future of IAEDB. The group consisted of Tony Best (Chair), Mike Collins, William Green and Kurt Vinterhoj. They were joined in their discussions by Chair, Jacques Sourieau and, from July 1995, Marianna Soulsami, and Secretary/Treasurer, Rodney Clark. Administrative support was provided by Richard Hawkes from Sense International. The group held a series of meetings and carried out two separate consultation exercises to enable members to express their views.

Information from IAEDB members

Many of the recommendations come from ideas presented by IAEDB members during the consultation sessions at the International Conference in Cordoba, in July 1995. Further information came from the questionnaire sent to all members in November 1995. The data from the questionnaire was analysed by William Green and presented to the group in January 1996. William then discussed the various ideas and put together the following recommendations.

Recommendations

The recommendations cover 4 topics: members, organisation, finance, activities.

Members We recommend that there are two type of members - individual and corporate.

1 Individual Members: Any person can register as an individual member. They have the benefits of receiving copies of 'Deafblind Education', other papers produced by the Association such as policy statements, information sheets, notices of meetings and workshops, reports from council and special interest groups. Members can join in Association activities such as conferences, networks and special interest groups. Individual members are invited to a general meeting every 4 years to hear about the work of their Council and Management Committee. Individual members are asked to pay an annual subscription, but this is not obligatory.

2 Corporate Members: Any association, society or institution may apply for Corporate membership. Corporate members have a place on the Association's governing committee, the Council, and may also be elected onto the Management Committee. Subscription fees are based on a sliding scale.

Organisation

3 Name: The name, IAEDB, no longer reflects the true nature of the association as it only mentions 'Education' and many members are concerned with services for adults and those providing vocational training, recreational, rehabilitation and social services. We recommend, therefore, a new name for the organisation, and suggest Deafblind International.

4 Structure: We recommend that the Association continues as an international organisation rather than dividing up into regional sections. It should create networks, based on regions, language or topics and the operation of these networks would be a major activity of the Association. They would organise the exchange of information between members and the development of knowledge through newsletters, reports and workshops.

5 Council: We recommend that the governing board of the Association be The Council. This would be responsible for all aspects of the Association and its activities. It would meet annually.

Members of Council would consist of a representative of each Corporate Member. In addition, any country that did not have a Corporate member, could have a representative on Council. They would be elected by the members from that country for a 4-year period or, if necessary, appointed by Council. The Council can also appoint additional members ('co-opted') if they have some additional specialist expertise (eg. chair of sub-committees).

6 Management: A small management Committee should be appointed by Council to carry out Council decisions and policy, and to make any necessary decisions between Council meetings. It would hold office for a 4-year period and should meet every few months.

7 Officers posts: We recommend that the officers, and their terms of office, remain as in the current constitution. They would be elected by Council, although all members would be able to send in nominations.

We also recommend that, where possible, no more than one principal function should be performed in any one country, and that all posts should have a maximum period before retirement.

The Management Committee would consist of the Officers (Chair, Vice-Chair, Secretary, Treasurer, Immediate Past Chair) and other people chosen by Council up to a maximum of 15 members. This committee would be responsible for preparing financial reports, budgets and operational plans, organising the election process, appointing and supervising any paid staff, organising formal reporting and strategic planning. The Committee would also be responsible for making decisions about association awards.

Finance

8 Strategy: We recommend that the overall financial strategy of the Association is to cover all basic core costs through subscriptions. Additional activities would be carried out when additional funding from grants or donations are available.

9 Administrator: We recommend the appointment of a part-time administrator to carry out much of the work currently undertaken by the Secretary/Treasurer, including responsibility for assisting with income generation.

10 Subscriptions: The income must cover these expenses. Our primary source of income is Corporate members. We recommend a sliding scale of subscriptions, based on the budget of the institution, and think this should be in the range of US\$200-5000. The optional individual subscription should be set annually by Council.

Activities

11 We recommend that the Association undertakes the following activities as 'core' activities:

- Organise an International Conference every 4 years.
- Publish the Journal 'Deafblind Education' regularly.
- Distribute information & publications.
- Develop and maintain Networks, and specialist geographic, topic and language Groups.

Other important activities should be carried out as time and finances allow:

- Promoting staff development activities.
- Promoting service development.
- Creating awareness of deafblindness.
- Developing policies relating to deafblind people.
- Achievement of status with International Governmental Organisations.
- Co-operation with other agencies to make most efficient use of resources.
- We recommend that IAEDB does NOT undertake the provision of direct services, nor should it provide training.

12 Planning: We recommend a Strategic Planning Group be established to provide Council with a plan of activities covering a 4-year period.

Conclusions

These proposals are intended to ensure that the Association changes to meet a changing situation. We have suggested that the organisation has a stronger leadership by redefining the Executive Council. A small management group will ensure all activities are carried out between Executive meetings. The Association activities would not change very much, but they will be more focused on doing what it is good at - creating and sustaining networks of colleagues.

All these proposals will be considered by the Executive at its meeting in Vancouver, Canada, in May. Members will be told of their decisions on these suggestions in the next issue of Deafblind Education.

Tony Best

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.

I wish to receive Deafblind Education in English

I wish to receive Deafblind Education in Spanish

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 _____

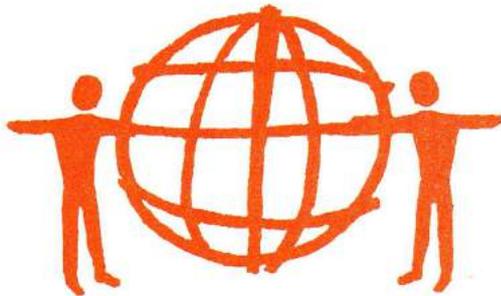
Signed _____

Name _____

Institution _____

Address _____

Tel _____ Fax _____



International Association for the Education of Deafblind People

CHAIR

Marjaana Suosalmi
Resurscenter
Mo Gard AB
612 93 Finspang
Sweden

VICE-CHAIRMAN

Michael Collins
Perkins School for the Blind
175 N Beacon Street
Watertown, MA 02172
USA

Antonio Rebelo
Casa Pia de Lisboa
Rua d. Francisco de
Almeida No 1
1400 Lisboa

SECRETARY/TREASURER

Rodney Clark
Sense
11-13 Clifton Terrace
London N4 3SR, UK

IMMEDIATE PAST CHAIRMAN

Jacques Souriau
CESSA Larnay
Biard
86580 Poitiers
FRANCE

National Contacts

ALBANIA

Elida Cangonji
Instituti Mediko Edukativ
Tirana

ARGENTINA

Gricelda Callegari
Instituto Helen Keller
Av. Velez Sarsfield 2100
Ciudad Universitaria
5000 Cordoba

AUSTRALIA

Heather Hewitt
University College
University of Melbourne
College Crescent
Parkville 3052
Victoria

AUSTRIA

Christa Heinemann
Osterreichisches Hilfswerk für
Taubblinde
1100 Wien
Humboldtplatz 7

BELGIUM

Marlene Daelman
KMPI Spermalie
Snaggaardstraat 9
8000 Brugge

BRAZIL

Angela Ribeiro
Escola de Educacao Especial
'Anne Sullivan'
Av. Conde de Porto Alegre 820
S. Vaetano do Sul
Sao Paulo 09500

BULGARIA

Vladimir Radoulov
Research Institute for Education
Cul. Tzakia 125 Fl. 5
1113 Sofia

CANADA

Stan Munroe
Canadian Deafblind and Rubella
Association
747 Second Avenue-East
Suite 4, Owen Sound
Ontario N4K 2G9

CHILE

Claudia Pumarino Cid
Las Azaleas 181
Las Condes
Santiago

CHINA

Li Pan
The Teacher Training Division
The Education Commission of
Hunan
Changsha
Hunan Province

COLOMBIA

Ximena Serpa
Calle 108 # 20A - 13
Bogota

CZECH REPUBLIC

Jan Jakes
LORM - Society for the Deafblind
K vadojemu 29
150 00 Praha 5

DENMARK

Solveig Jensen
Aalborgskolen
Kollegievej 1
9000 Alborg

EGYPT

Father Youhanna Henein
Holy Mary Queen of Light
Organisation
PO Box 80
Sidi Gaber
Alexandria

ESTONIA

Olga Ilgina
Low Vision Centre
Ravi 18
EE0007 Tallinn

FINLAND

Marja-Leena Saarinen
Rehabilitation Centre for
Deafblind Children
Kukkumäntie 27
40600 Jyväskylä

FRANCE

Jacques Souriau
CESSA Larnay, Biard
86580 Poitiers

GERMANY

Dietrich Bunck
Bildungszentrum-für-Taubblinde
Postfach 710460
30544 Hannover

GHANA

Marion N Obeng
Centre for Deafblind Children
PO Box 33
Mampong-Akwapim

GREECE

Efrossyni Zafiri
59 Messogiou
Athens 11526

HUNGARY

Dorka Kiralyhidi
Hungarian Deafblind Association
Budapest 1146
Ajtosl Durer sor 39

ICELAND

Bryndis Viglundsdattir
PO Box 5086
Skiholt 31
105 Reykjavik

INDIA

Beroz N Vacha
Helen Keller Inst. for the Deaf &
Deafblind
c/o Municipal School, Near 'S'
Bridge
NM Joshi Marg, Byculia (West),
Bombay 400011

INDONESIA

Nicola Crews
D/A Rawinala
JL. Inerbang 38
Batu Ampar, Kramat Jati
Jakarta 13520

IRELAND

Ray McLoughlin
The Anne Sullivan Foundation
40 Lower Drumcondria Road
Dublin 9

ISRAEL

Ruth Rosenbluth
Keren OR INC
Abba Hillel Silver 3
Ramot 01
91234 Jerusalem

ITALY

Rossano Bartoli
Legga del Filo D'Oro
Via Montecerno 1
60027 Osimo-Ancona

JAMAICA

Germaine Lynch
The Salvation Army School for
the Blind
57 Mannings Hill Road
PO Box 562
Kingston 8

JAPAN

Sadako Imamura
Yokohama Christian School for
the Blind
181 Takenomaru
Nakaku, Yokohama

KENYA

Boniface Lentoimaga
Kabernet School for Deafblind
Children
PO Box 128
Kabernet

LITHUANIA

Irena Matuliene
Lithuanian Association of the
Blind and Visually
Handicapped
Labdariu 7/11
Vilnius

MALAYSIA

Simon Rajendran
St Nicholas Home
Locked Bag No. 3031
4 Bahan Jermal Rd
10090 Penang

MALTA

Irene Schembri
8 Mannarino Road, B'kara

MAURITIUS

Dr K Hazareesingh
Mauritius Child Care Society
The Oxford/Mauritius Child
Care Project
Phoenix

NETHERLANDS

Ton Visser
Instituut voor Doven
School Rafael
Theerestraat 42
5271 GD St Michielsgestel

NEW ZEALAND

Elsie Purdue
Homai College, Browns Road
Private Bag
Manurewa, Auckland

NIGERIA

Dipo Bailey
Investment House
21/25 Broad Street
PO Box 9334, Lagos

NORWAY

Elisabeth Olafsen
Norwegian Central Team for the
Deafblind
P.b. 8042 Dep.
0031 Oslo

PHILIPPINES

Dante Capistrano
Philippines National School for
the Blind
Galvez Corner Figueroa
Pasay City 1300

POLAND

Jozef Mendrun
Polski Zwiazek Niewidomych
Zarząd Gkowny
00-216 Warszawa

PORTUGAL

Antonio Rebelo
Casa Pia de Lisboa
Rua d. Francisco de
Almeida No 1
1400 Lisboa

ROMANIA

Prof Valeriu Mare
Department of Psychology
The University Cluj-Napoca
Str. Kogalniceanu Nr. 1
3400 Cluj-Napoca

RUSSIA

Valeri Chulkov
Institute of Correctional
Education, Russian Academy
of Education
119834 Moscow
Pogodinskaja str. 8

SENEGAL

Gilbert Tending
EMPPi Centre Verbo-tonal de
Enfants Sourds
BP 3883 Dakar R.P.

SINGAPORE

Koh Poh Kwang
Singapore School for the Visually
Handicapped
51 Toa Payoh Rise
1129 Singapore

SLOVAKIA

Janka Sarisska
Evanjelicka pomocna skola pre
hluchoslepe deti
082 07 Cervenica 114
Slovakia

SOUTH AFRICA

Dr Johan van der Poel
Pioneer School for the Visually
Handicapped
20 Adderley Street
6850 Worcester

SPAIN

Pilar Gomez
CRE Antonio Vicente Mosquete
Programa de Sordociegos
O.N.C.E.
Paseo de la Habana 208
28036 Madrid

SRI LANKA

Mr J S David
Sri Lanka Churches' Council for
Child Care
490/2A Havelock Road
Wellawatte
Colombo 6

SWEDEN

Elizabeth Abouda
Ekeskolan
Box 9024
S-700 09 Örebro

SWITZERLAND

Birgit Jentzsch
Stiftung für Taubblinde
Heim Tanne
Führstrasse 15
8135 Langau a A

TAIWAN

Frank Chang
National Taiwan Normal Univ.
Department of Special Education
162 Hopping East Road, Sect. 1
Taipai

TANZANIA

Elly Macha
Tanzanian National Committee
for the Deafblind
PO Box 22408
Dar es Salaam

UGANDA

Mbuusi Jackson
PO Box 14278, Kampala

UNITED KINGDOM

Rodney Clark
Sense, 11-13 Clifton Terrace
London N4 3SR

URUGUAY

Carmen Cirintana
Zuffrategui 990, Montevideo

USA

Michael Collins
Perkins School for the Blind
175 N Beacon Street
Watertown, MA 02172

ZIMBABWE

Robert Chimedza
Ministry of Education and Culture
PO Box 8022, Causeway
Harare

NORDIC REGIONAL OFFICER

Kurt Vinterhaj
NUD
Slotsgade 8
DK-9330 Drønninglund
DENMARK

Partial funding for this publication was made possible by Perkins School for the Blind, Watertown, Massachusetts and the Conrad N Hilton Foundation, Los Angeles, California. The IAEDB is indebted to them for their support and would also wish to acknowledge the support received from the United Nations towards Deafblind Education and towards providing expert assistance to developing countries.