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Conference issue**

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.

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CHAIRMAN'S MESSAGE

It is with mixed emotions that I write my final Chairman's Message. I am obviously sad that my period as IAEDB Chairman will soon be over but I also feel excited about the way the organisation is developing and the possibilities for the future.

When I started as Chairman I said that my priority for the IAEDB was to assist the strengthening of international relations and contacts within the field of deafblindness. With an ever changing population, in terms of both causes and ages, it is vital for professionals throughout the world to maintain contact with each other, to provide each other with support and to keep on top of all international developments. The IAEDB must play a leading role in this and I am sure that the re-structuring process we are currently undertaking will result in an IAEDB that can play this role even more effectively.

Although I would rather consider the future than look back at the past there are some highlights from the last four years that I would like to mention. The Executive Meetings in Boston and Bydgoszcz and the European Meeting in Potsdam were all particularly successful. Especially pleasing is the



increasing number of colleagues and friends from the countries of Central and Eastern Europe; the meetings in Poland and Potsdam did much to stimulate their involvement in IAEDB. In Europe the European Deafblind Network goes from strength to strength and we have seen the creation of the EUCO Unit as an initiative from an IAEDB sub-committee. The amount of services in South America continues to grow and the conference in Cordoba will surely help this.

A number of international organisations are assisting developments in Asia and Africa and

more and more people from these regions are contacting our Secretariat. Many of the services in Asia receive support from Beröz Vácha at the Helen Keller Institute in Bombay. We were all tremendously sad to hear of the death of her husband, Nari, who passed away in May and I would wish to convey our best wishes to her on behalf of the IAEDB.

As we look to the future it is promising to see an increasing number of international organisations involved in the development of services for deafblind people. A meeting in Portugal in January 1996 will bring these organisations together to consider co-operation and collaboration. As IAEDB re-structures itself it will undoubtedly play an important role in these developments.

So we will meet in Cordoba in July. I hope as many of us as possible will be there to stimulate service growth in South America, to discuss the future of the IAEDB, to strengthen our relationships and to elect the next person to hold the privileged position of IAEDB Chairman.

Thank you and best wishes.

Jacques Souriau

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EDITORIAL



This is a bumper edition of *Deafblind Education* with a number of in-depth features on a range of topics.

There is a focus on deafblind education in Latin America. This is most relevant for this issue as the IAEDB World Conference is about to be held in Cordoba, Argentina. The main article is a report by Profesora Graciela Ferioli and Licenciado Osvaldo Bertone, on educational services for people with visual impairment and additional disabilities in Latin America. The report was based on a detailed survey carried out by ULAC and ONCE with the support of the Hilton Perkins program and gives an extremely detailed analysis of education services throughout the region. We also include more specific reports on the work being undertaken in a number of centres throughout Latin America. This section is also being printed in Spanish.

There is a report outlining some of the first developments of services for elderly deafblind people. This includes mention of provision in Australia, Europe and North America.

We have a major article which I think will be very well read - by Ton Visser from the Rafael School at Sint Michielsgestel. He gives a description of the current developments in the care of deafblind children at his institute. This includes reference to the theory and principles that underlie the educational programmes used, as well as outlining the organisational model, work on language development and communication, development of living and social skills, the use of individual plans, and training and research.

We also have two publication announcements; on a publication detailing work in Italy from a scientific context, and on eight major projects in England. I hope that such reviews can be a feature of *Deafblind Education* in the future, and welcome suggested material for this.

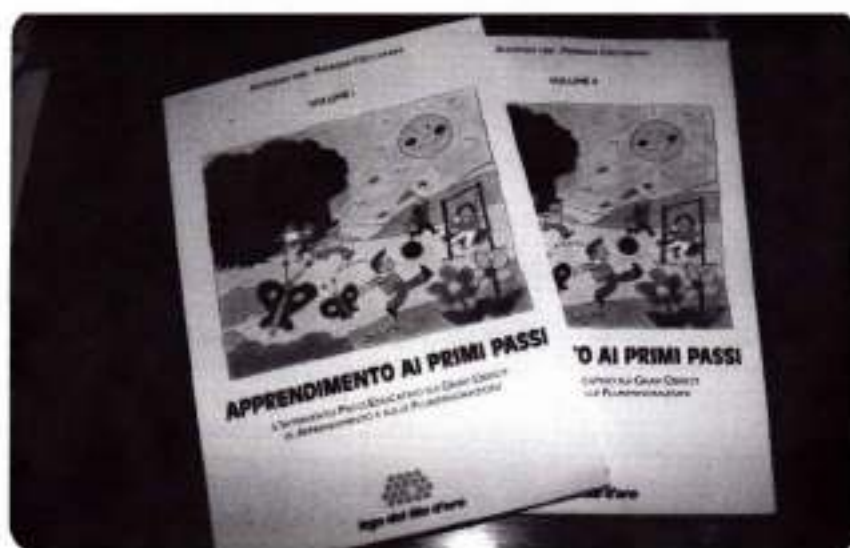
I hope to meet some of you in Argentina in July - but whether or not you are able to join in the IAEDB World Conference I hope to hear from you about activity in your countries.

With best wishes to you all.

Malcolm Matthews

Recent Publications

First steps to Learning



There has been a marked increase in the number of contributions from psychologists and behavioural and cognitive scholars concerning disability. Their aim is often to link practice and theory; to provide a level of competence and methodology and techniques which are rooted in theory, rigour and the power of explanation.

This book is by Nisi and Ceccarani, 'First Steps To Learning: Psycho-educational intervention on severe

learning deficits and multiple impairments', follows this approach but with three differences. The procedures illustrated have been taken from the Italian situation and the work at the Lega del Filo d'Oro. A section describes the interventions used there with deafblind people and the philosophy of rehabilitation. There is a thoroughness to the descriptions of techniques taken from the behavioural and cognitive approaches.

Sharing a Regional Approach

Sense and the Department for Education in England have published a major report entitled 'Deafblind Education: Sharing a Regional Approach: Report of the GEST Project - Educational Provision for Deafblind Children: 1992 - 95'.

This report is over 300 pages long and describes the activities undertaken by eight regional groups of local authorities working to develop educational provision for deafblind children. Each group outlines their activities - particularly in the areas of identification of deafblind children and training. In some of the groups there is a particular focus on intervention. The report does not describe models of good practice in detail but rather provides an account of the effect on provision of authorities working together at a regional level, an evaluation of the process and outcomes of this, and the ways in which short term funding can provide an impetus for action.

Conference proceedings

Proceedings from the Conference 'Hearing Assessment and Aural Rehabilitation of Multiply Handicapped Deaf Children' which took place in Ancona, Italy in November 1994, are now available in the international journal 'Scandinavian Audiology' Volume 24, 1995, supplement 41.

Jan van Dijk was among the speakers at the Conference which included sessions on objective procedures and assessment; behavioural procedures and assessment; rehabilitation - fitting procedures for auditory prosthesis, educational goals and training methods, and case presentations.

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, Interveners 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.

IAEDB award presented to Jan van Dijk

To mark the presentation of the IAEDB award to Jan van Dijk, in the following two features Deafblind Education reviews the impact of his work and returns to the Instituut voor Doven to examine its current developments

On 19th March 1995 I had the honour, on behalf of the IAEDB, of presenting Jan van Dijk with the IAEDB Distinguished Service Award 1995.

Jan van Dijk is known all over the world for his work with Rubella Deafblind Children at the Instituut voor Doven, Sint Michielsgestel, the Netherlands. In 1958, he became a teacher at this institute and later on, because of his interest in deafblind children, he studied at the Perkins School for the Blind, Boston, United States of America.

His work with rubella children led him to publish an extensive study of rubella children in Australia: "Rubella Handicapped Children" (1982), which is a good example of how a developmental profile can be linked to common aetiology. A follow up study, published in 1991, described how, within the same sample of rubella children, two sub-categories could be identified. Jan van Dijk calls these "Victors and Victims". These studies are an illustration of the overall approach of the Sint Michielsgestel institute: an accurate differential diagnosis is the key for a good educational programme. Besides, an ongoing assessment of the children's skills and acquisitions will feed back the predictive value of the instrument used for the diagnosis itself. This back and forth movement between education and assessment seems to be a crucial element in the process of adapting to the children's needs and expectations.

As everybody within IAEDB knows, the influence of Jan van Dijk on the programmes for deafblind children is enormous all over the world. Through lectures during Conferences, staff training sessions, publication of books and articles, his knowledge has spread among the professionals working with deafblind children in many countries. Many staff have been trained at the Instituut voor Doven and still use at home what they have learned there. In most of the institutions or services for



Jan van Dijk (left) receiving the IAEDB Award from IAEDB Chairman, Jacques Souriau

deafblind children, theory and practice reflect this influence. The main aspects of this approach are:

- the importance of being sensitive to the child's expression;
- the necessity of ordering and structuring the child's day in place and time as a way to make the world meaningful instead of chaotic;
- the necessity of providing the children with new symbolic or linguistic skills within social interactions rather than using only stimulus-response programmes.

Jan van Dijk's influence on programmes for deafblind children is enormous all over the world.

Of course, each country and institution makes its own use of these basic principles. New developments in research about communication development have led to expansions, transformations or reorganisations of these basic principles. New fields of human knowledge (sociology, ethnology, ethics etc.) contribute to defining the approach towards deafblind education, but the very basic principles which are expressed in this institute are strong enough to define the professional's attitude towards deafblind children.

So this IAEDB award is meant to express our debt to Jan van Dijk's extraordinary contribution to improving the quality of life for deafblind children. Jan van Dijk and the Instituut voor Doven, because of the quality of the work they have done, showed to all the world that rubella children can be educated successfully and that providing deafblind children with adequate educational services is not socially questionable. So, on behalf of the IAEDB, I was very proud to present this award, which is the expression of our gratitude.

Jacques Souriau

The care of deafblind children at the Instituut voor Doven in Sint-Michielsgestel, the Netherlands

Ton Visser, from the Rafaël Department at Sint Michielsgestel, describes current developments and approaches to the care of deafblind children within the department.

Description of Current Developments

Historical background

The Instituut voor Doven (IvD) first came into contact with children who were deafblind in the early 1960s, when staff from the Instituut visited Potsdam (Germany) and Poitiers (France) at the request of the then Board of Management of the Instituut, to learn about the most appropriate ways of caring for and educating deafblind children. The Instituut took the plunge in 1962 and admitted the first deafblind children. In 1968, following a period in which it was sometimes necessary to sleep two children to each bed, a building was made available specially for these children: the Rafaël department for children who are deafblind was born.

During its first 20 years the department grew slowly, but its development began to accelerate after 1981. In recent years the number of children admitted to the Rafaël department has continued to increase and now numbers 70. One change has been the fall in the proportion of children with Rubella syndrome in recent years, from around 80% of our population ten years ago to some 50% today. Many children admitted in recent years have different syndromes: Zwiellerger syndrome, Goldenhar syndrome, CHARGE association and Usher syndrome. It naturally makes a great difference whether a child is deaf and blind from birth or whether one or both function losses developed at a later stage in the child's development.



School Rafaël is the deafblind department of the Instituut voor Doven which is based in the town of Sint Michielsgestel

Theory and principles underlying the educational programme

The need for an adequate theoretical framework has always been recognised at the Rafaël department, and we have therefore constantly been on the lookout for theories which could help increase our understanding of the behaviour and development of children who are deafblind, and which above all could help us to place the experiences built up by parents and staff at our Instituut into some sort of ordered framework. Our hope is that this framework will increasingly enable us to use these experiences in the development of an optimised educational programme.

At the moment, we draw on three theories in particular. First is the deprivation theory. This theory describes various forms of deprivation and their

impact on the development of children. Sensory deprivation means that a child observes the world in a very fragmentary way, often failing to process adequately the multitude of information with which he or she is bombarded. The child's response is often to shut off from certain stimuli while focusing on others in a one-sided way in what appears to be a complete fixation.

Another common problem in the early years of life of children who are deafblind is social deprivation, where the development of the early mother-child relationship is disrupted by frequent hospitalisation or the poor physical condition of the child. This results in oversensitivity to certain stimuli, and this again can easily lead to atypical behaviour patterns, so that 'normal contact' with others gradually becomes more difficult for the child.

A second theory which offers many useful insights is the 'bonding theory'. This focuses mainly on the importance of correctly 'seizing' and interpreting behaviour used by the child to try and make intentions clear. If the carers then respond adequately to this behaviour, the child develops an 'inner working model', as it were; the child learns how the carer will respond and is thus able to develop a feeling of competence, a realisation of how to become an active 'conversation partner'. In recent years the contribution of "the transactional model of development" (Emde & Sameroff, Vogel, etc.) has been significant for our department. In this model developmental problems are related over time to a continuity of rigid or dysfunctional child-environment interactions.

The third theory underpinning much of our thinking and actions is the social learning theory. This theory emphasises the major influence of the social environment on the development of a child. According to this view, the child's development is influenced by three factors: by reinforcement of the behaviour which the child itself displays, by instruction and by imitation. The main problem affecting the development of deafblind children is that they frequently fail to discover the contingencies between different events. Consequently they often learn in a very limited way through observation and imitation of other children and adults, and develop virtually no form of spontaneous learning. The social learning theory is used increasingly within our department for the further operationalisation of the bonding theory; in our view, the two theories complement each other very well.

Diagnostics

In the debate on the most adequate form of caring for and educating children who are deafblind, diagnostics should be seen as a 'keyword'. Without a very clear and cohesive insight into a child's limitations or handicaps, development potential and his or her optimal learning conditions, it is not possible to set up an adequate programme. At the Instituut voor Doven, the Diagnostic Centre was founded to meet this need. The Centre's tasks cover both diagnostics and the treatment of children and adults and are carried out by six working teams: the Medical Service, the Audiological Centre, the Vision Centre, the Intake and Differentiation team, the Educational Psychology and

Counselling team and the Developmental and Behavioural Problems Prevention and Treatment team. Frequently they work together on a multi-disciplinary basis. The Rafael department works very closely with all the six working teams.

Several staff in these teams have specialised in issues relating to the care and education of deafblind children. Each of the diagnosticians is expected to be capable both of conducting adequate and reliable diagnostic examinations within their own discipline and of 'translating' their findings into an individual treatment plan for each child. They are also expected to be capable of communicating their findings directly to the child concerned and/or their parents.

We are constantly on the lookout for theories which could help increase our understanding

For special educational and psychological diagnostics, the 'broad band procedure' is used. Both 'free field' and 'standardised test' procedures are employed: conversations and interviews with the parents, observations at home, in the living group and classroom, checklists, inventories, tests, etc. The essential point is that each form of diagnostics should lead to concrete recommendations with respect to the treatment plan for each child. The entire approach at all times retains the character of a 'teach and test model'. Recommendations which have been 'translated' in the Individual Educational Plan (IEP) into concrete agreements with respect to the child are subsequently put into practice and evaluated for their effectiveness. Where necessary the recommendations are adjusted, possibly in combination with further diagnosis.

Organisational model of the residential home and Rafael school: From integrated living and learning to peripatetic support within the mainstream education system

To mark the opening of the renovated residential homes and the new Rafael school building, we invited a number of 'experts' from outside the department and from outside the Instituut voor Doven to perform a strength/weakness analysis of our care provision based on

their wide experience. These experts were people working in the care of mentally handicapped persons, children with severe psychological and psychiatric difficulties and children and adults who are deafblind. The findings of their analyses were surprisingly concurrent in a number of respects. On the one hand there was great appreciation of the high quality of the care, the capacity for very methodical working and the high commitment of the staff; on the other hand, there was concern that the wide range of care options offered appears to lead to overstimulation of a not inconsiderable group of children. This overstimulation derives in part from our tendency when planning the I.E.P. to be guided mainly by the developments undergone by the child in a given - sometimes specific - area (e.g. communication development/language development), and less by the emotional and social development of the child. As a result, many children in our care were plunged too quickly into what, for them, was an overly large, complex and unpredictable world. This 'criticism' of our working method largely confirmed the thoughts which had already been voiced in many internal discussions. The upshot was a realignment of our organisation in the direction of what we have called the 'continuum model'.

This is a model in which the living and learning/school environment are precisely tailored to each child's individual needs. It is thus a model which can offer the child an environment which is surveyable and predictable to the extent that this is important for the child, and which can be broadened in stages. This gives the child an adequate sense of security and enables the child to integrate new experiences, in terms of understanding and skills, with experiences gained earlier.

At one end of the continuum is the care provision, in which the living group/residential situation plays a crucial role and learning/the school is completely integrated in the activities taking place within that living group. At the other end of the continuum is the service provided for children who use only the school programme or who have been integrated in another form of education and receive peripatetic support. Between these two extremes are a number of 'intermediate steps'. In his workshop in Córdoba (at the IAEDB World Conference) Walther Tibosch, head of our residential setting, will give more extensive information about our "child based organisation".

Interaction, communication and language development

It is the view of our department that the 'heart' of the care and education of children who are deafblind still lies above all else in our commitment to helping the children to develop the best possible level of communication, and to bring them to the highest possible degree of language development.

In recent decades major strides have been made in this development process, and we have also seen a number of 'waves' in our department. During the department's first two decades much attention was devoted to what we could call mutual interaction between child and educator, or the development of conversation. The educator tries to "seize" what the child has tried to express and gives him or her the correct communication code for this before going on to react as adequately as possible to the communication.

For deafblind children, developing independent living skills offers the opportunity to achieve a feeling of 'being somebody'.

In the last ten years a great deal of work has been done on the development of the various communication codes, including the use of objects of reference, drawings/pictures, reference books and on the further development of a wide variety of calendars. These developments are of vital importance because they make it possible, with increasing success, to give the child the communication code which is both the most effective at present, and which also lays the foundation for the next step in the communication development process.

One thing which we have observed in recent years is that attention is often given to the code at the expense of attention to the essence of communication and the development of mutual interaction. Our contact with four experienced colleagues in the European Working Group on Communication has made this clear, particularly to myself. Through in-service training activities, however, we are now working to shift the emphases once again.

The use of signs is currently the subject of much study. Some children and young people will initially - and



Susanne van Doorn with her teacher, Angela Eeffink, at the calendar table

sometimes permanently - have to communicate through signs matched to their abilities. Colleagues at the Aalborgskole in Denmark recently published an article on this subject in this journal. Our approach is largely in line with theirs. Little or no research has been carried out in Dutch situations into the use of the Dutch Sign Language by pupils with a visual disability, nor into the way in which visual disabilities influence the use of the Dutch Sign Language. What adaptations in use occur in the Dutch situation is still unclear.

Over the course of the years we have made a distinction between communication development and language development. Whereas in communication development the primary focus of attention is on learning to communicate as adequately as possible, in language development the main focus is on learning the Dutch language and, in particular, learning to read. This may sometimes be one and the same objective, but in many cases this is not so. Of prime importance is that everyone knows what objective he or she is aiming for at each moment. Experience has shown us that insufficient attention to this point can result in us investing a very great deal of time in teaching a very limited number of words to children who proved to have very little capacity for this, while these words often turned out to be of little actual use in their communication after leaving school. We also found that with other children, devoting too little highly explicit and

skilful attention to 'learning language' can hold them back at an unnecessarily low language development level and, in particular, stop them reaching the level of reading which they must be regarded as capable of achieving.

The development of independent living and social skills and the development of pre-vocational and vocational training

In addition to the development of the most adequate communication skills possible and the highest possible language level, the development of skills to live and work in less restrictive environments also occupies a key place in our programme. For children who are deafblind, developing the highest possible level of independent living and social skills offers the opportunity to achieve a feeling of 'being able to do something themselves' and of 'being somebody' - in other words, to develop a feeling of competence and autonomy. Until around five years ago this aspect of development was given much less attention than the development of communication skills. In particular, visits to colleagues where the programme for children who are deafblind is linked to centres for visually handicapped persons, showed us that they had developed this and gave it more attention than we did. When planning and equipping our new school building, therefore, we made use of the opportunity to give this component of the programme the room - literally - it needs to develop to the full.

From the age of 12 children in our

Centre can now follow a programme which we have called 'supported living and working'. The following are some of the features of this programme:

- Activities within the programme are structured in such a way that the child is required at all times - to however slight a degree - to use his or her own initiative. This is in order to prevent 'learned helplessness' as much as possible.
- Many activities are simple and routine in nature. This means that staff constantly have to search for activities which fit in with the world of the child, which are as varied as possible and yet which are routine in nature and result in a product which is recognisable for the child. Continuous error analysis must be used to make clear which aspects require extra training and/ or where the skill to be learned needs to be modified.
- As far as possible, the activities should show a logical relationship with each other. For example, potatoes are sown in the garden and harvested again later. In the woodworking room, boxes are made for storing the harvested potatoes. In the kitchen the potatoes are boiled, fried, chipped or made into chips and frozen. The same products are then bought in the shop, etc.
- Maximum attention should be devoted in these lessons to the development of social skills such as waiting, sitting still in one place, asking for help in the right way, helping each other, leading certain activities as a pupil, etc.

The use of Individual Educational Plans

In the Rafaël department working with Individual Educational Plans (IEP) has assumed a central role in the working method. In principle the IEP is redefined once a year in an IEP meeting. During these meetings the parents, given their extensive experience with their child, generally have a large and important contribution to make regarding the details of their child's IEP.

Each IEP consists of a 'personal profile' and a description of each aspect of the individual's development programme. In the personal profile an attempt is made in one or two pages to give a description of the child or young person in which their personality is characterised as sharply as possible. It also examines the way the environment should be tailored to him



Fraichel Kleinmoedig preparing to bake an apple tart

or her, in order to ensure well-being and opportunity to develop. An important element of the personal profile is the description of what is regarded as the developmental potential of the child concerned.

The descriptions of each aspect of the individual development programme give an indication of the baseline for evaluation and of the objectives and methodology. The programme file belonging to each IEP contains a detailed description of the working method for each programme component. In the Rafaël department, a number of inventories have been developed in recent years which enable the development of the children to be monitored. These 'home-made' lists

chart the socio-economic development of the child, the development of socialisation and modified behaviour, a number of aspects of personal independent living skills and the development of a feeling of competence. The lists give a good impression of how well the programme is matched to the capacities of the child and indicates the presence of overstimulation or understimulation. In this way the list has a strong signalling function. The advantage of the lists, all of which are developed in collaboration with a large number of experienced staff, is that they chart very accurately certain developments in the children. Many standardised lists developed for this purpose are based on overly large

development steps and are thus less suitable for this particular group of children. On the other hand, the obvious drawback of the Rafaël lists is precisely that they are not standardised.

In principle these lists are developed for each IEP-meeting. Apart from these lists, standardised inventories and, where possible, standardised tests are also used every two to three years. The aim at the moment is to record the results in a sort of pupil monitoring system, making it easier to chart the development of each child over a large number of years.

Working with co-ordinators (school) and heads of the group homes in the role of supervisors.

The book 'Staff Supervision in Services for Sensory Impaired Children and Adults', which appeared last year, contains an extensive description of several aspects relating to supervision within the Rafaël department. One of the main reasons for deciding to work with co-ordinators/supervisors was the observation that, in our situation, the visual and hearing function loss, the learning and developmental difficulties and the medical problems are very different and complex. Staff cannot be expected to possess all the understanding and skills necessary to be able to draw up an IEP themselves for every child and to be able to implement that plan unaided.

Of the multitude of tasks which co-ordinators carry out, two are seen as the most crucial. In the first place they are responsible for adequately co-ordinating the contributions of the many people involved (e.g. parents, teachers, group leaders, ophthalmologists, audiologists, etc.) for monitoring continuously that the correct priorities are set within the programme. Their most essential task, however, remains the supervision of staff in the workplace itself: demonstrating, coaching, observing - possibly with the aid of video - and discussing their observations, etc. Our experience is that this is still the only truly effective way of 'learning the trade' properly.

Training

Training is seen as a keyword both in our department and in our Instituut as a whole. Everything stands or falls on having the capacity to train new staff well and to offer experienced staff the opportunity for ongoing in-service training. I have already indicated in discussing the co-ordinators/heads of group homes that we regard the supervision of staff in the workplace as something which should play a key role here.



Ton Visser, Director of the Rafaël School, Instituut voor Doven, Sint Michielsgestel, The Netherlands.

In order to be able to place staff training and supervision of parents in a more concrete framework, this school year we have started recording elements of our programme, as I have described it above, on paper and video. We have released a few staff from their normal duties on several days a week for this purpose. The primary aim of 'recording on paper and video' is to place the large amount of experience possessed by many people in some kind of order, to make it visible and accessible to others. We hope that this will make it easier to transfer this experience to parents and colleagues. These programme elements will also serve as modules in the training of new staff members. I know that several colleagues in a number of departments throughout Europe are currently working on similar projects. With the aid of the Euco Unit, I hope we shall succeed in making these products available to each other.

Scientific research

The Instituut voor Doven has traditionally devoted a good deal of attention to scientific research, and has for many years had its own Research and Development department.

Two research projects are currently underway in the Rafaël department. One project, led by Dr. J. Lancioni, is investigating the best ways of providing children with the necessary support to enable them to carry out tasks as independently as possible. A large number of research projects have been completed in our department under Dr. Lancioni's leadership in recent years; all these projects concluded with a publication.

The research project led by Marleen Janssen was set up to investigate how competent behaviour can be fostered in deafblind children in interactive situations. This project attempts to make

the children more competent in the use of their skills for showing their likes and dislikes clearly. At the same time an attempt is being made to teach adults to recognise when their behaviour towards the children has the effect of being supportive. In other words: what things that I do as an adult help the child to express himself or herself more competently and what things that I do make that more difficult for the child?

Conclusion

At the request of the editor of Deafblind Education I have tried to present an outline of the work carried out within our department for children who are deafblind.

We consider it very important to receive feedback on our work

No single article - no single book, for that matter - can however do justice to all the ideas and experience of parents and staff, nor to their dedication to put them to good use in the upbringing and education of deafblind children. We are therefore always delighted to be able to welcome colleagues to our Instituut who wish to share our experiences. Above all we consider it very important to receive their feedback on our work. This is one of the ways in which we hope to be able to continue learning and developing. In order to maximise the benefit from visits from colleagues, and also to enable normal day-to-day business to continue running smoothly, we have organised these visits into three 'visitors weeks' per year.

One item which cannot go unmentioned is a very extensive article by Jan van Dijk, Marleen Janssen and Catherine Nelson entitled 'Deafblind Children', in which they describe the diagnostics, theoretical background and a number of important aspects from the educational programme for children who are deafblind.

In conclusion: the objective of all the efforts made within the Rafaël department is to achieve the best possible 'quality of life' for all the children concerned, both now and in the future: a life in which they experience what it is to be 'heard and seen', a life in which they are allowed and are able to take pride in being human beings. It is my hope that this is the feature which more than any other characterises the 'programme' of the Rafaël department.

A. Visser
Director, Rafaël School

Teaching Expressive Language

Elan Zarechnova writes about teaching language to pupils who have lost sight and hearing. The article discusses the processes operating within the classroom, and outlines the model used to develop expressive and written language skills at the Sergievo Posadsky Rehabilitation Centre for the Deafblind in Russia.

I shall start by explaining the system of teaching deafblind children formal language through connected text. A child perceives their first fingerspelt words simply as signs. These are included in a story which is presented to them by pantomime and signs. Their vocabulary at this period consists of 20 - 30 words which relate to well known objects.

The same vocabulary is used in further practical work on the grammatical structure of language when a text is written using these words. Sentences in this text are simple and are logically connected to describe a defined situation in the deafblind child's life.

A formal method of parallel texts is used to teach deafblind children. One text is written by a teacher and is a "teaching model", the other is a "self-generated text" written by the student. This method was worked out by Professor Ivan Sokolyansky.

New grammar categories are then introduced into the teaching texts according to a predetermined system. This process continues until all grammatical categories are assimilated. The students write their own texts in accordance with the teaching texts, but use their own content to express their own experiences.

These texts later become their first reading books. Students gradually progress to reading texts with contents external to their experiences. This method was worked out by Elena Goncharova, a researcher from the Institute of Special Education.

Perception of such a text, the analysis of the text and the construction of the student's new statement are closely related. The formation of language and reading activity in a deafblind child occurs through the development of skills in describing a situation, asking questions and characterising actions.

In the formation of language in deafblind students during lessons in

language development and reading they acquire the elements of written narrative. Forming narrative language in deafblind students is one of the main problems in the general language development of sensorily handicapped children. We pay great attention to students' motivation in language and cognitive activities and to building good conditions for their self-expression through language.

The fingerspelt and written statements of deafblind students reflect their own experiences or those of another student in the class, and are expressed in the student's self-generated language in different forms, such as compositions, letters, diaries and other autobiographical stories. This will later help them to understand the experiences and language of others when they are presented in written text.

The communicative direction of the whole language activity is very important. We aim to create a language environment and organise language activities outside, as well as within, the Rehabilitation Centre.

We are working to diversify the direction of student's communication to a range of situations and communication partners. This is encouraged through creating special conditions where students have to use in practice the knowledge they have learned in lessons.

The general aims of the work on language are as follow:

- 1 Creation of the conditions for self-expression within the framework of language activity in order to increase motivation.
- 2 Organisation of the student's language environment, their language and their cognitive activities in order to intensify the communicative direction of their language.
- 3 Intensification of language activity in different forms and with different language partners.

A method of teaching "talking" was an important approach to emerge from our experimental work in lessons on language development and reading. We think that the organisation of connected language and the outcome of the production of an independent statement depends on the organisation of their learning. This is adapted to the peculiarities of language development in deafblind children.

Outline of the Method of Teaching "Talking":

- 1 **Preparatory work on the organisation of watching a situation/ event/trip/play etc.** This includes:
 - a) Organisation of students' cognitive activity. The main aims of this are to:
 - define the objects of observation;
 - make short comments about the object;
 - discuss the possibilities for exploring the object, bearing in mind the ability to also use tactile and vibro-senses, residual sight and hearing, taste and smell;
 - define the modes of recording or memorising the observed object.
 - b) Organisation of deafblind students' language activity, with the aim of removing possible language difficulties. In this stage the students are given a limited set of new words and are acquainted with the phrases these can be used for to describe the object.
- 2 **Group observation of a situation/activity/event, and a discussion of what was observed. The main aims of this stage are to:**
 - activate all possible modes and sources for the observation of an object for the deafblind child;

- provoke associations with what they have observed, read about, or experienced in the past;
- prompt students with questions on their own statements;
- organise communication between the children about what they observed.

3 Individual self-generated work

The aim of this is to enable students to give a connected description of a situation or event, and to present their impressions of the observation. This stage involves:

- a) A teacher presents a task and states the form in which the students should write about it (eg a letter/story/diary entry).
- b) Supporting sources in writing letters and stories are provided, such as plan, key words and language patterns.
- c) In order to preserve high motivation in this work a careful balance is sought between independent self-generated work, the teachers' participation, and the use of instructive material.

4 Analysis and editing of the text.

The main aims of this section are to:

- form a desire in students to perfect written text;
- teach a sequence and method to correcting mistakes;
- continue the formation of linguistic concepts which are necessary for the perfection of written text.

a) In order to analyse a text the students have to know a minimum of special concepts, such as text composition, idea and plan. Students acquire this theoretical knowledge during several years of education. They are also taught to use this knowledge while writing their own self-generated texts.

b) The work on perfection of the written text starts from the shared activity of a teacher and a student, with the teacher in the leading role. The teacher initially analyses deficiencies, explains in detail the cause of mistakes and helps to correct them. At the later stages the student suggests a plan of analysis and works with the teacher's support. Further work becomes more complicated, and the model of parallel texts is used. The

teacher gives students a text-model written on the same theme and asks them to compare that text-model with their own texts, make a comparative analysis, and correct the mistakes in their texts. Gradually the teacher's role in this work diminishes. After some time, when the students have a better command of the skills of perfecting written text and the quality of language is higher, we progress to a method of stylistic experiment in which we present the students with an incorrect text and asks them to correct it.

Students' motivation increases as the teacher's role gradually diminishes

5 Text review

The aims of this section are to:

- teach deafblind students to make detailed and short oral and written reviews on the writing of their friends and their own writing;
- to form the skills of evaluation of written text in accordance with certain language norms.

The first "reviews" are student's oral statements after reading their friend's text. They consist of several words or two or three sentences. In this case it is important not to give a detailed analysis but to present a personal opinion. This is done by students before the teacher checks the texts, so the teacher's opinion does not dominate. The main task of the teacher is to regulate students' statements, to help them in the language arrangement, and to draw conclusions. Oral work leads to written reviews.

At first the written reviews consist of the students' answers to the teacher's questions. After this the teacher suggests a scheme for a review. The students learn the scheme and use it themselves.

6 Text revision

This aims to perfect the skills of independent revision of written texts using theoretical knowledge and practical experience. The main goal of a teacher at this stage is to stimulate students' independent

work to the maximum.

Undoubtedly a new text will not be free from deficiencies but it will favourably differ from the first attempt. In future this text can be revised again in various lessons as the deafblind student's language level improves. In our opinion this motivates the student to work more than in a situation in which the teacher demands correction of all mistakes to create a perfect text.

7 Creation of a new text

This stage aims to awaken an interest in the creation of a text and to produce an understanding of its necessity. Our experience confirms that to solve both specific grammatical problems and to help general development, children's work, written in general stages, needs repeated and continuous analyses after a short while and then again in the future. Good examples of this are autobiographical writings where deafblind students describe their feelings after losing their hearing and sight, write about relatives or about future plans. This work is done over several years as we return to the first texts, rethinking them and revising them.

To some extent this approach fills a gap in the restricted perception, lack of knowledge about the surrounding world, and the low level of cognitive and language activity of students as a result of their dual sensory impairment and language retardation.

In connection with this we decided to include the following stage in the method of teaching "talking":

8 Retrospective analysis of a text and creation of a new text

Experimental work on this approach showed positive results: the quality of narrative language in deafblind students of senior age-groups became higher. Written and oral statements increased considerably in length, contents of text became deeper, and the quantity of structural and language deficiencies in text arrangement decreased significantly. This proves the potential of this approach in teaching deafblind students of senior age-groups and that it is possible to start this work in younger age-groups.

The EUCO Unit

The European Coordinating Unit for Staff Development in Deafblind Services



The EUCO unit offers information and co-ordination 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

The services provided by the EUCO Unit include the EUCO Unit's Bibliography of NUD's international library on deafblindness and related topics. It is almost completed and all our subscribers have received one. The Inventory - Directory of Resources has been available for some time now, and subscribers have also received a copy of this.



The inventory is updated each year and enables you to locate, as the network widens, the range of resource people you may need to contact.

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 130 organisations, institutions, schools and individuals in Europe and other parts of the world that provide services to deafblind people. It has information about a number of your colleagues in deafblind work and on current projects. It also contains four different charts which give you an overview of the services and programmes offered to deafblind people.

For new entries or changes to entries in the Inventory, please ask for a questionnaire. For those of you wishing to become subscribers, contact:

The EUCO Unit, c/o NUD, Slotsgade 8, DK. 9330 Dronninglund, Denmark.
Phone + 45 98 84 34 99
Fax + 45 98 84 34 88.

Coming Events

Course on Communication Development 22-26 June 1996

1st Announcement!

A course on communication development is planned to take place in Paris in June 1996.

The organisers are the members of the European working group on communication: Marlene Daelman (Belgium), Anne Nafstad (Norway), Inger Robroe (Denmark), Jacques Souriau (France) and Ton Visser (Netherlands) in co-operation with The EUCO Unit and the CNEFEI (Centre National d'Etudes et de Formation pour l'Enfance Inadaptée).

The course is planned as an international discussion forum for professionals who are responsible for developing education and intervention programmes in the field of congenital deafblindness and related areas (blind children without speech, autistic children, children with multiple impairments for instance).

Members of the working group on communication and invited guest speakers will lecture. Different aspects in communication development will be covered, including social interaction and the emergence of communication, pre-verbal communication and verbal communication. For the practical application of the work there will be video illustrated guidelines for intervention.

The working language will be English.

Young Deafblind Leadership Seminar in Strasbourg 10-17 Sept 1995

A planning meeting was held at NUD in March 1995 with the EUCO Unit as hosts and with representatives from Spain, England, Scotland, Belgium, Italy and Denmark.

On the agenda was the planning of a seminar in Strasbourg for young deafblind persons. The theme was how young deafblind persons gain access to information within their own organisations in order to enable them to participate in the decision making process.

The seminar will be hosted by the European Youth Centre in Strasbourg from 10-17 September 1995 which means arrival on Sunday 10 September and departure the following Sunday 17 September 1995.

Invitations and further information will go out by the end of May to organisations for young deafblind people in each country, not only in the European Union, but to all member states of the Council of Europe. The organisations will then nominate one official participant to represent the deafblind population from their country.

For further information please contact: Jackie West, Mobility International, Rue de Manchester 25, B-1070 Brussels, Belgium.
Tel: +32 2 410 62 97
Fax: +32 2 410 68 74

or William Green, Lega del Folo d'Oro, Via Montecorno 1, 60027 Osimo (AN), Italy.
Tel: +39 71 71 31 202
Fax: +39 71 71 71 02.

Helios subventions for staff development activities

Once again it is time to consider applying for Helios subventions for your staff development activities during the second half of 1995 and 1996.

From the secretary of the European Deafblind Network (EDbN), Rodney Clark, we have received a letter indicating that there is likely to be money available for activities out of this year's budget for activities taking place in the autumn 1995. Applications for support for your staff development activities should be sent to The EUCO Unit as soon as possible. We will then endorse them and send them to the EdbN secretariat.

Priority areas in 1995 and 1996 are efforts to obtain social integration and

an independent way of life (called sector 5 in the Helios II General Rules) e.g. accessibility, transportation services, sports, leisure and cultural activities. In 1996 priority will be given to specific problems and needs for people with severe or multiple handicaps and ageing disabled people.

Staff training for training of teaching staff will be focussed on in 1995 and 1996, and also training of people involved in the rehabilitation process and social integration of disabled people. The training of vocational guidance and training staff has priority in 1995.

For activities planned for 1996 your applications should be sent to us before the 15th August 1995.

Remember that activities planned to take place in Austria, Finland and Sweden are now eligible for support, as they are now EU member countries. Only activities which take place in the second half of 1995 can receive subventions.



Kurt Vinterhøj

The EUCO Unit will supply you with additional information and application forms upon request. Please call or write!

Europe and interpreter training

A European Committee on Interpreter Training and Services for Deafblind People is working to achieve agreement on the key components of training. Live Fuglesang (Central Team for the Deafblind, Norway), William Green (Lega del Filo d'Oro, Italy) and Stewart Simpson (CACDP, England) explain the reasons why this is needed.

There are many reasons why it is essential to have European agreement on the key components in training interpreters for deafblind people. In essence these stem from a fundamental need to establish common goals and to ensure basic human rights of equal

access and opportunity. The meeting of representatives from European countries has already provided examples of excellence and neglect. There is no doubt that wide disparities of provision exist in Europe. For example, the interpreter provision in most Scandinavian countries is supported by intensive training and by guaranteed rights to interpreting time for deafblind people which, in turn, has provided a career structure and remuneration for those who interpret. It is a situation which contrasts sharply with other countries - some of which do not provide even the most basic of training or formalised interpreting.

Of course in any comparison between European countries there has to be a recognition of cultural differences and priorities. Such differences only emerge when attempts are made to discuss the key

components of interpreter training. But the essential emphasis is on the positive aspects of sharing problems and reaching solutions, of gathering together and developing training materials, of providing a network of contacts and support, and of facilitating knowledge and understanding. By creating an environment in which representatives from different countries are made aware of each others needs and provision there is a rich supply of support towards common goals. Comparison of one country to another can be used as a political lever - not only in achieving harmonisation of interpreter services but also in striving for excellence. It is these goals - harmony and excellence - which are essential in establishing the basic human rights of access and equality. Together they are the absolute essentials for developing interpreter services.

The European Usher Syndrome Study Group meet in Dronninglund

38 people gathered in Dronninglund in Denmark during May for the 8th meeting of the European Usher Syndrome Study Group. The meeting had an interesting agenda, including presentations from:

Claes Möller (Sweden): *Early screening and diagnostication. Recent work on balance problems.*

Sandra Davenport (USA): *Explaining the genetics of Usher syndrome to patients and their relatives.*

Claes Möller (Sweden): *Latest findings in genetic research and news on Usher syndrome, type III.*

Thomas Rosenberg (Denmark): *A large scale survey of hearing impairments in RP-patients.*

Gunilla Henningsen-Rönblom (Sweden): *Group discussions as therapeutic method for young people with Usher syndrome.*

Sissel Grønlie (Norway): *Mental health and Usher syndrome.*

There were also presentations and discussion of local work on Usher syndrome. A session with concluding remarks and discussions of future work of the European Usher Syndrome Study Group closed the meeting.

More on this in the next issue of the EUCO News Bulletin! Proceedings of the meeting will be available later in the year. For information please contact:

Mary Guest
Acting Secretary
EUSGG
c/o Sense, 11-13 Clifton Terrace
Finsbury Park, London N4 3SR.
Fax: +44 171 272 3862

Networking

Are you connected to the Internet?

Did you know that there is a discussion forum concerned with deafblindness on Internet?

All you have to do to get connected is:

- Start from your Internet line as usual.
- Choose to send a message, and on the line 'From' you write your own e-mail address.
- At the line 'to' you must write:
deafblind@ukcc.uky.edu
- Finally at the line 'subject' you write:
subscribe
- All that you need to do now is to send the message.
- In 24 hours you will get a confirmation that you have joined the discussion forum. Make sure to confirm this within 48 hours, otherwise your subscription to the list will be cancelled.

After having confirmed your subscription you will get all the information which is on the list. You may send both personal letters and list-letters for the other subscribers to the list.

If you think this sounds like a good idea, join the list to see what is going on. You can always disconnect if you do not wish to continue as a subscriber.

Conference notices

Parents' Conference

The European Deafblind Network (EDbN) invites parents of deafblind children to the European Parents' Conference in Madrid from 7-10 September 1995.

The Spanish organisation Organización Nacional de Ciegos (O.N.C.E.) has very generously offered to host the conference and to provide accommodation. There will not be any conference fee or accommodation expenses.

During the annual EDbN meeting in 1994 parents discussed what will happen to their children when they are no longer around to take care of them,

and they felt that this important topic needed to be discussed at a conference. The theme 'Congenitally Deafblind Adults - Needs and Opportunities' will focus on job possibilities, occupation and living conditions etc. as the deafblind children become adults.

The anticipated number of participants will be 60 parents from Europe. The conference language will be English. More information can be obtained from Kurt Vinterhøj (EUCCO Unit), Gini Cloke (UK), Miriam Bruggeman (Netherlands) or Wolf-Dietrich Trenner (Germany).

Usher in the Deaf Community Project

Aston University, Birmingham, England

4 October 1995

Usher syndrome is a major cause of deafblindness in the adult population.

During the past 4 years this project (run jointly by Sense and the British Deaf Association) has worked to promote understanding of Usher syndrome in the Deaf community. This conference aims to share information and materials developed as well as the insights gained. The programme will include approaches to training and a presentation of materials about Usher, specifically designed and tested by people with Usher and aimed at the Deaf community. A new video

produced by the project workers will also be launched at this conference.

The conference will be of interest to Social Workers in Sensory Impairment, Educators, Health Workers (in particular those delivering health services to Deaf people), people with Usher syndrome and their families, and all organisations working in the sensory field.

For further details please contact Francesca Bondy at Sense, 11-13 Clifton Terrace, Finsbury Park, London N4 3SR or call on +44 171 272 7774 (voice) or +44 171 272 9648 (minicom).

Educational Services for People with Visual Impairment and Additional Disabilities in Latin America

Licenciado Osvaldo Bertone and Profesora Graciela Ferioli present the findings of research into the provision of these specialist services

Introduction

For many years institutions in several Latin American countries worked without appropriate support with people with visual impairment and additional disabilities. Despite these efforts the lack of suitable institutional and professional contacts resulted in services in need of improvement. In the 1980's these institutions began to make specific demands of the International Non Governmental Organisations working in the region, in particular the Hilton/Perkins Program, ULAC and ONCE. The result of these demands was the identification of the need to undertake a survey of how people with visual impairment and additional disabilities were served throughout the region. This survey was co-ordinated by ULAC and ONCE and supported by a grant from the Hilton/Perkins Program.

Objectives of the Survey

Knowing about the quality of services for people with visual impairment and additional disabilities in Latin America was the main goal of the survey. To accomplish it the following objectives were specified.

- 1 To establish which institutions dealing with any kind of impairment provided a service to people with visual impairment and additional disabilities.
- 2 To describe some individual characteristics of people with visual impairment and additional disabilities served by these institutions.
- 3 To study the personal characteristics and backgrounds of teachers working with people with visual impairment and additional disabilities.
- 4 To locate among the schools that serve people with visual impairment and additional disabilities the ones which have early intervention services for children under 3 years old with a visual impairment with or without additional disabilities.
- 5 To establish how many infants receive early intervention services in the institutions identified according to objective 4.
- 6 To study the personal characteristics and backgrounds of teachers working in early intervention services for children with visual impairment with or without additional disabilities.
- 7 To describe the main aspects of institutions that deal with people with visual impairment and additional disabilities in the region.

Method

Key people were identified in each country to send out and collect questionnaires.

The survey consisted of five questionnaires, in Spanish and Portuguese, each one no longer than one page of A4.

Questionnaire 1 dealt with basic information and the services being offered by each institution. Institutions answering that they offered services for visually impaired people with additional disabilities were sent

Questionnaire 2 to obtain more specific information.

Questionnaire 3 concerned early intervention services and

Questionnaires 4 and 5 looked at the training of teachers.

Results

The results showed that there were 163 institutions serving people with visual impairment and additional disabilities. In these institutions 2,220

FOCUS ON LATIN AMERICA

people were enrolled as pupils or participants in educational or rehabilitational services. Within this survey the classification of these people has been done according to their two main impairments, that is to say, those that restrict more than the others ability to perform an activity in the manner, or within the range considered normal, for a human being. This is the normal definition.

Table 1 shows the distribution of visually-impaired people according to additional disabilities enrolled in the 163 Latin American institutions.

Clearly, in this table, predominant percentages are those of people with motor (33.11%) and mental retardation (34.7%) as additional disabilities. Deafblind people (13.78%) and those with psychological disorders (18.38%) showed lower percentages. The percentages of people enrolled in institutions revealed approximately the incidence that these multi-impairments have in the population. That means that Latin American institutions are admitting these people regardless of

their additional disabilities.

Table 2 (opposite) shows the distribution of institutions and pupils or participants according to additional disabilities by country. Countries were ranked by the number of visually impaired people with additional disabilities.

This survey also required data about features of teachers working in institutions. Most teachers were women and their average age was 35 years old. Professional degrees were categorised according to their specialism regarding multi-impaired education, including deafblindness. Only 5% of teachers reported a specific degree; 22% were teachers of the deaf or the blind; 42% were physiotherapists, medical doctors, social workers, and others with little specialism and 31% were professionals without qualifications relating to health or education, or simply without a professional degree.

Areas of specialisation of teachers were studied as well. Orientation and Mobility and Daily Living Skills were not frequently cited, but can be critical

skills in instructing a multi-impaired person to live independently. This situation reveals that the curricula is not greatly functionally orientated towards promoting independent living skills.

Early intervention services were found in 50% of institutions that deal with people with visual impairment and additional disabilities. Within these services, 50% of children were visually impaired and 28% were visually impaired with additional disabilities. That means there is a significant proportion of children with these kind of disabilities using these services.

It is important to say that we found problems in understanding the early intervention concept used by the respondents, because we observed answers that included children older than 6 years old, maybe included because they were in the early stages of child development.

Most teachers in these services are not specialised in early intervention, which may be connected to the recent creation of these services in Latin American countries.

		Deafness	Hearing Impairment	Neurological Impairment	Physical Impairment	Mental Ret. Mild - Moderate	Mental Ret. Sev - Profound	Psychological Disorders	
Visual impairment and additional disabilities	Blindness	105	45	330	93	271	114	255	
	Visual Impairment	107	49	247	65	272	114	152	Total
	Total	306		735		771	408	2220	

Table 1 Distribution of 2,220 clients of 163 Latin American institutions by their visual impairment and additional disabilities.

Country	Institutions with people with		Enrolled people with				
	Visual impairment and additional disabilities	Deafblindness	Visual impairment and additional disabilities	D-B	VI-Mo	VI-NR	VI-PD
Brazil	39	24	593	137	211	172	73
Argentina	43	25	405	54	134	129	88
Mexico	12	6	378	29	126	84	139
Colombia	17	12	255	51	59	116	29
Chile	12	5	226	16	101	96	13
Costa Rica	11	1	95	1	28	53	13
Peru	14	3	75	5	19	47	4
Bolivia	3	3	50	8	17	21	4
Uruguay	3	1	50	2	17	20	11
Guatemala	1	0	31	0	6	11	14
Paraguay	1	1	30	3	8	6	13
Ecuador	4	0	27	0	9	11	7
Dominican R.	3	0	5	0	0	5	0
Total	163	81	2220	306	735	771	408
Key: D-B Deafblindness VI-Mo Visual Impairment and Motor Disability VI-MR Visual Impairment and Mental Retardation VI-PD Visual Impairment and Psychological Disorder							

Table 2. Distribution of Institutions and Pupils by Countries.

Conclusion

An inference from the data collected reveals that educational services for people with visual impairment and additional disabilities have increased within the last 20 years in Latin American countries. From this we should ask two questions: First, why have the number of educational services increased recently in spite of the economic crisis of Latin American countries? Second, have these services had adequate space, well-trained teachers and suitable materials to

accomplish the main goals of education for multi-handicapped people?

It is possible that the cause of this increase in services is not from the awareness of government authorities about the rights of multi-handicapped people, but due to the demands of parents. Governments, under pressure from parents, may have begun the opening of services even when they did not have adequate buildings, trained teachers and materials. So these services now need to be helped by organisations.

Although there are many areas in

which support is needed, we think the first should be teacher training. From this training, educational authorities, parents and others may become aware of what is necessary to teach these children properly. Finally, we hope Latin American institutions will work with each other to improve their services as they are helped by International Organisations. We think this survey is a significant contribution because it presents thorough information and identifies what needs to be addressed.

COUNTRY REPORTS

Argentina (Buenos Aires)

The Fatima centre was founded in 1988. There are currently 11 deafblind people, ranging from two to 19 years old, using the centre.

As it is a well established centre it acts in many ways like a resource centre, receiving more and more requests from different parts of the country and helping to increase services throughout Argentina. Currently being developed are programmes in education, early attention, visual and hearing stimulation and assessment. Staff training is a priority in order to maintain the quality of the services for deafblind people.

The immediate project is to build an Early Attention Centre for deafblind children and to open a Residential Programme for deafblind adults. The Hilton/Perkins Program is supporting this development.

Argentina (Cordoba)

The Helen Keller Centre in Cordoba has trained blind, visually impaired, multi-sensorily impaired and deafblind people since 1944. The centre has a Technical Department and an Education Department. The programme for deafblind and multi-disabled people offers an individual programme from early years to the age of 21.

The parents play an important role, working with the Technical and Education Departments to establish the education needs and priorities of the children. The centre works towards giving everybody the opportunity to lead an independent life and to be integrated within society.

Costa Rica

The Special Education Programme in Costa Rica started in 1949 but it was only in 1994 that the first programme for deafblind people started. It is hoping to get help for this project from national and international organisations interested in supporting developments in other countries to help it to be more successful at present and in the future.



Columbia (Santa Fe de Bogota)

The Centre for Visually and Hearing Impaired people was created in 1991 to offer educational opportunities for deafblind children. Programmes are available for children from two months to 17 years old. The centre is keen to improve the quality of services for deafblind people by looking to integrate them within the Community so that they can be as independent as possible. They have an Educational Programme which has four levels: Stimulation, Learning (academic), Pre-school and vocational.

Venezuela

The deafblind programme started in 1991 through PAINS, the programme for deaf people with additional needs. There are currently five deafblind children aged between four and 15 being supported by the programme. This will increase as the programme develops with the support of the Hilton/Perkins Program.

There are plans to develop a new programme for 13 deafblind people aged between two and 17 and also to create a National Organisation for Deafblind Adults as part of the POSCAL project.

Brazil (Cambuci)

The Association for Visually and Hearing Impaired people was founded in 1983 and currently has programmes for deafblind children and deaf children with additional disabilities.

There are 15 deafblind children and an individual programme is designed for each of them. There is an interdisciplinary team comprising services in phono-audiology, therapy language, psychology, social work and family support. They also offer a Sign Language and Braille service.

Bolivia (Santa Cruz)

APRECIA is a resource centre, founded in 1976, for blind and visually impaired people. The philosophy is to strive towards as independent a life as possible by supporting people in the community. They have five programmes (Education, Rehabilitation, Prevention, Extension and Workshops) and are working with 175 people.

The programme for deafblind and multi-disabled people started in 1989. There are currently four deafblind and eight multi-disabled children between five and seven years old within the programme. There are also five deafblind adults involved in the workshops. Sense International is supporting developments with a training programme for the next three years.

Older people with dual sensory loss

A Department of Health working group in England is planning to produce a document which describes good policy and practice in providing services for older or elderly people who have both a sight and hearing impairment. At the end of last year I tried to find out as much as I could about services specifically for acquired deafblind and elderly deafblind people from around the world. There was not much to report but I made a short presentation to the working group along the following lines. I feel sure there must be more that I should have known about, and I would be very interested to receive further information on this subject.

- Malcolm Matthews.

The incidence and prevalence of hearing and vision loss is high among older adults and increases with age. The Royal National Institute for the Blind in the UK in 1991 published research indicating that 45% of people with a visual impairment aged over 75 had problems hearing¹. The number of older and very elderly people in many Western countries is increasing. The problem of age related sensory loss in most countries is not adequately recognised, although loss of vision and hearing is often emotionally devastating to older adults and usually leads to loss of independence and

reduced quality of life.

A search of the NUD² library database for English language papers related to deafblindness and older people revealed only one article.³ The EUCO⁴ Unit's Inventory revealed one Project clearly concerned with deafblindness and older people.⁵

In 1993 I visited the Association for the Blind in Victoria, Australia. I was very impressed by the Association for the Blind producing a leaflet on hearing loss.⁶

Even more impressive is two of the Association's low vision clinics, at Kooyong and at Geelong, also offering

an audiological service "since hearing loss so often accompanies vision loss". Help includes assessment, prescription of aids, advice on practical living and help in coming to terms with sensory loss.

Another service that recognises the nature of sensory impairments officially opens this month in Londonderry, Northern Ireland. This is the first shop-front drop-in service in the UK involving statutory and voluntary agencies working with blind and visually impaired people, deaf and hard of hearing people, and deafblind and dual sensory impaired people. Staff include a social worker for the visually impaired, a social worker for the hearing impaired and two rehabilitation workers, as well as workers from the Royal National Institute for the Blind, the Royal National Institute for Deaf people (including an interpreter), Guide Dogs for the Blind and Sense. Services include advice, information and support for people with sensory impairments of all ages and their families and this includes elderly people.

In the USA the Helen Keller National Training Team conducts conferences and seminars for the caregivers of older persons including the staff of nursing homes, staff of senior citizens groups and family members. These people usually know about "geriatrics" but do not understand sensory loss and this is the dimension introduced by the training team.

The Helen Keller National Centre has another very interesting development. Usually older adults have limited access to rehabilitation or independent living services that are

The Information Centre for Acquired Deafblindness

Ole E. Mortensen writes:

The Information Centre for Acquired Deafblindness (as opposed to congenital deafblindness) is a little more than one year old. It is one of 11 similar Danish centres on various disabilities (there is also one for congenital deafblindness, for instance). The main purpose of our Centre is to provide information for professionals of all kinds and organisations in the field, as well as the public in general, on practically all subjects with relation to acquired deafblindness. This can range from communication through to technical (and other) aids and medical research findings. We write articles and other publications, make videos, issue a quarterly newsletter, arrange meetings and small symposiums on special topics,

and we initiate, supervise and co-ordinate research projects in order to create and find new knowledge and insights.

We are funded by the Danish Association of County Councils. The staff consists of two full-time employees and a part-time secretary, and we are situated at an independent unit at the Institution for the Deaf near Copenhagen.

We are VERY interested in making international contacts and in participating in international networking.

Ole can be contacted at the Institutionen for Dove, Generatorvej 2 A, DK-2730 Herlev, Denmark. Phone +45 42 91 91 11. Fax +45 42 91 27 28.

Deafblindness in old age - A project in the Netherlands

Last year the final results were presented of a project called "Deafblindness in old age". Research had been done on the number of deafblind people in homes for the elderly in the Netherlands. Information was sought on the numbers of deafblind persons and the problems that staff have in providing care.

180,000 people live in homes for the elderly, 3,000 of them are deafblind. Most workers do not know how to communicate with deafblind people or where to go for help and information. Most deafblind elderly people are very isolated and need more care than the other residents. The workers need staff training relevant to

this group of deafblind people.

To meet this need for training another part of the project was the production of a video and instruction book. In the video we see assistance and support being given to four deafblind older people. The film gives a good account of ways in which help can be provided. In the instruction book the problems of aged deafblind persons are described and tips given that can lead to solutions.

These publications, entitled "Ongehoord en uitzichtloos" are for sale in Dutch from Stichting Doofblinden. If there is enough interest an English language translation will be considered.

designed to assist them adapt to or cope with sensory loss. The Confident Living Programme⁷ provides older adults with opportunities to learn coping strategies, gain support and become linked to service providers. Model community based programmes are held in five areas in community facilities including a hospital and a recreation centre. Older deafblind people are involved in structured educational groups in order to help provide emotional and information support, and to help retention of quality of life and independence. As well as this support provided by the groups, some participants have received support in dealing with their loss from the group facilitators and local agencies contacted as a result of the Programme.

From these model programmes a Participant Manual has been written. The curriculum in the manual includes six modules: an introduction, the eye, the ear, coping with vision loss, coping with hearing loss and coping skills.

A one week facilitator training programme has been developed and more programmes set up. A Facilitator Manual has also been developed with contents on how to prepare for and conduct a Confident Living Programme as well as covering the six topics in the Participant Manual in detail. The purpose behind the material and approach to presenting and resources are provided for each module.

In Spain some services for deafblind people are received by elderly people -

for example guide interpreter services. A residential service for elderly deaf people or a service for elderly blind people may have a resident who is deafblind. A professional guide interpreter trained by ONCE can provide training and practical support for up to a two week period. Training from an orientation and mobility professional can also be provided for the deafblind person in a residential situation. This can include development of daily living skills and will involve one or two days a week of training for perhaps a month.

In the Netherlands all persons with a dual sensory loss can get help from the social and rehabilitation services for blind and partially sighted people. Low vision and audiological examination have been found to lead to solutions to a range of problems. Many of the elderly deafblind are very old. Sometimes simple solutions such as a low vision aid for reading or a volunteer to take the person for a short walk or to provide conversation is significant in improving their quality of life. For some people a very tailored service is required and discussions are underway involving special houses for the elderly blind, elderly congenitally deaf and deafblind older people.

In Denmark, as in most places, older people with sight and hearing impairments have been largely ignored until now as they have not been recognised as having a specific disability. In one county there is a project to locate each and every person

with acquired deafblindness. The local deafblind counsellor knew of 16 adventitiously deafblind people. The project has located about 300 persons with a combination of a vision and hearing impairment⁸. (The population is approximately 600,000 people.) Of this group 260 are over 70 years old. Identifications were made through extensive contact with all the local professionals - such as "home nurses" (a nursing service for old, sick and/or disabled people) - and departments of social affairs. The next step in this project is to establish whether people receive the support they need.

Older people with both a sight and hearing loss have been largely ignored until now. They have been regarded as just ageing and have not been recognised as having a specific disability. This is now changing.

With thanks to Bernadette Wynne, Asuncion Leyton, Anneke Balder and Ole Mortensen.

References

- 1 Interviewers' assessment of (569) respondents' hearing in Bruce, McKennell & Walker "Blind and partially sighted adults in Britain: the RNIB survey" Vol. 1, RNIB, England 1991.
- 2 Nordisk Uddannelsescenter for Dovblindepersonale, Denmark, 1994.
- 3 Belser, Glass & Luey "Beyond refuge: Coping with losses of vision and hearing in later life", Helen Keller National Centre & University of California, USA, 1989. (I have since been informed of a publication by the Helen Keller National Centre "Identifying Vision and Hearing Problems Among Older Persons: Strategies and Resources".)
- 4 European Coordinating Unit for Staff Development in Deafblind Services "Inventory: Directory of Resources", 1994
- 5 Anneke Balder, The Netherlands, "Deafblindness in old age".
- 6 Leaflet "Ageing and Hearing Loss", Association for the Blind, Victoria.
- 7 Contact the Older Adult Program, Helen Keller National Centre, South Central Regional Office, 4455 LBJ Freeway LB#3, Suite 814, Dallas, Texas 75244, USA.
- 8 Some of this group may be outside the definition of deafblind used in Denmark.



Association Nationale
Pour les Sourds-Aveugles



Association de Patronage
des Etablissements de Sourds
et Sourds-Aveugles - Poitiers



I A E D B
International Association
for Education of Deafblind

Conference Notice

European Seminar

Adventitiously Deafblind Adults: Philosophy and priorities in the development of the basic services

**Poitiers, France
March 22 - 26 1996**

It is acknowledged that deafblindness is a rare handicap that necessitates a unique approach to education, training and rehabilitation for developing daily living skills and social participation. Yet less well understood and provided for amongst this specialism are people who are adventitiously deafblind.

Throughout Europe the services available for people with adventitious deafblindness must be improved and developed. Exchanges on practices and co-ordination of initiatives are necessary to raise the quality and efficiency of Services.

The European Seminar will pursue reflections on the development of services for people who have become deafblind. It will mostly focus on the definition of Special Services and on the best strategy for their establishment and development.

It will be suitable for professionals working with adults with adventitious deafblindness, service planners, service users and families. Held over five days, it will comprise of workshops, conferences and visits.

The language used will be English, with French interpreters upon request.

For further information on this Seminar, contact:

**Seminar IAEDB - ADB,
1331 Av. des Hauts de la Chaume,
86 280 - Saint Benoit,
France.**

Tel: + 33 49 43 65 34,

Fax: +33 49 37 99 41

News

National Association of Intervenorers in the UK

On 11 February 1995 the first ever United Kingdom Intervenorers Conference was held at Sense Midlands, Birmingham. Fifty-five intervenorers from throughout the country attended the conference, which was organised by Local Education Authorities (from Hereford and Worcester, Staffordshire and Shropshire), the RNIB and Sense.

The guest speaker, Lois Hammel from Canada, spoke about the Canadian Association of Intervenorers, how it was established and the work it undertakes. There were a number of workshops on issues such as communication, the parents' perspective and aromatherapy.

During the Conference delegates

divided into regional groups to meet, support and exchange information. Regional representatives were selected.

As a result of the Conference the regional representatives met, on 29 April, with Local Education Authority representatives, Jonathon Griffiths from the RNIB, and Jenny Fletcher and Eileen Boothroyd from Sense. At this meeting of the co-ordinating group it was agreed to create the National Association of Intervenorers.

The Association will act as a support network and will work towards ensuring the acknowledgement of intervention as a recognised profession in the UK.

A further meeting of the co-ordinating group will take place in October and it is hoped that there will be a second National Conference in 1996.

For further information, or advice on how to establish associations of intervenorers in other countries, please contact:

Jenny Fletcher
Sense Midlands
Tel +44 121 456 1564
Fax +44 121 452 1656.

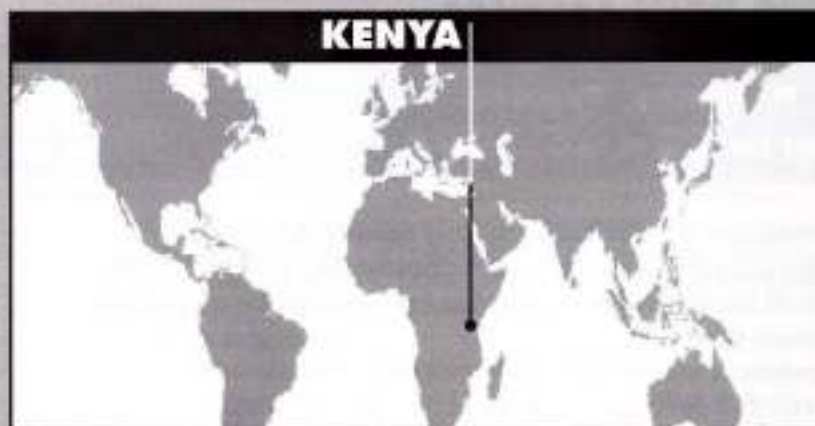
'Accepting the Challenge'

Australian Deafblind Conference 30 April - 3 May 1995 in Sydney, New South Wales.

More than 60 deafblind people, carers and professionals this year attended Australia's third deafblind conference. A constitution for Australia's first national organisation for deafblind people was accepted by the conference.

Vision-Hearing Impaired Deafblind Australian Council (VHIDBAC) has as its objects the encouragement of self-organisation and self-determination by deafblind people and the provision of a national forum for the deafblind community. Its committee has three deafblind members, one of whom is the President. VHIDBAC was charged with a number of tasks by the conference, including working with the World Blind Union to develop a symbol for use on white canes or guide dog harnesses.

The conference was arranged by the Royal Society of New South Wales and is held every two years.



In developing countries work with disabled people is often made difficult by a lack of reliable statistics. Although attempts have been made in East Africa to determine the number of disabled people there are still no real statistics available.

According to statistics used in developed countries it can be assumed that a country the size of Kenya (population 23 million) should have more than 5,000 deafblind people. At present we know of only 60, mostly children. We have to ask ourselves therefore, where are the other deafblind people?

In an attempt to answer this

question, the Kenyan Deafblind Services Committee, working together with the Ministry of Culture and Social Services, started a small project in one district, Nakuru, to try and identify deafblind people. This district was chosen because it already had good assessment and medical services. It was envisaged that the project would be in 4 phases:

PHASE 1:

This Phase began in 1992 with 2 seminars to create awareness and train social workers.

PHASE 2:

Social workers at village level spread information and organised screening.

PHASE 3:

Medical screening of identified cases. More than 30 centres have so far been visited, screening a total of 1,305 people aged between 5 months and 80 years old. Of these more than 50 have been identified as deafblind.

PHASE 4:

Follow up.

The project has now almost reached the end of Phase 3. As expected, many people with an ENT or eye problem have turned up for screening. Apart from helping these people to get treatment the project has so far been an important exercise in public awareness. Many parents previously unaware of the educational assessment services in the district are now enlightened and can make efforts to have their disabled children in appropriate school programmes.

Some of the deafblind children identified have already been referred to the Kabarnet School and, as the project moves into the final, follow-up, phase, the Deafblind Services Committee now has the task of assessing more closely the cases of deafblind adults and deciding if any intervention is necessary.

Penny May Kamau

CANADA



The Canadian Deafblind and Rubella Association celebrates its 20th Anniversary this year and is planning a number of celebratory

events.

In April 1975 a group of 22 parents of deafblind children met at the W. Ross Macdonald School in Bradford,

Ontario. The parents were from the provinces of British Columbia, Saskatchewan, Manitoba and Ontario. From that meeting the Association was born.

The Association owes much to the inspiration of Peggy Freeman and Margaret Brock, the parents who founded Sense in the United Kingdom, and who made numerous contacts with the first leaders in Canada.

1995 also marks the 10th Anniversary of the first independent living residence for deafblind people in Canada. This residence is now called McInnes House, after its prime mover and first Executive Director, John McInnes.

Stan Munroe

Sense International

Professional Development Programme

Sense International, created in 1994 to assist in the development of services for deafblind people throughout the world, is pleased to announce details of its International Staff Training Programme.

Organised in association with RNIB Condoover Hall School, the Royal School for Deaf Children, Margate and the Universities of Birmingham and London, the Professional Development Programme will take place in the United Kingdom from 15th April to 26th May 1996.

A unique feature of the Programme is that it will be different for each participant. An individual training programme will be structured according to the particular needs of each individual. Time will obviously be spent with other participants, but the Programme will offer individual placements at a number of centres throughout the UK. There will also be a series of lectures and seminars with the most experienced professionals from the UK.

Participants should have experience of working with deaf, blind or deafblind people, be currently working in a school or organisation involved with sensory impaired people or should have a current, or future, leadership role. In addition participants should have a recognised professional qualification in their home country and must be able to demonstrate a good knowledge of the English language.

The Programme is offered free to people from countries with developing services, for whom all costs apart from travel to the UK and personal expenses will be covered. A certain number of scholarships may be available to cover travel to the UK but applicants are encouraged to seek alternative means of financing this. Applicants from other countries will be expected to contribute towards the cost of the Programme.

THE DEADLINE FOR APPLICATIONS IS SEPTEMBER 30th 1995.

For further information and details of how to apply please contact Richard Hawkes or Asunción Leyton at:

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THE PRINCESS ROYAL CENTRE
4 CHURCH ROAD
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**The International Association for the
Education of Deafblind People (IAEDB)**

NOTICE OF GENERAL MEETING

The next General Meeting of members of The International Association for the Education of Deafblind People will take place at Cordoba National University, Cordoba, Argentina on Sunday 9 July 1995, at 1700-1900 hours. Buses will be available to transport people from the centre of Cordoba, where the hotels are situated, to the University campus.

The agenda is given below.

By order of the Executive Committee

Rodney Clark, Secretary/Treasurer, 1 May 1995

AGENDA

1. Apologies for Absence.
2. Chairman's Report 1991 - 1995.
3. Audited Accounts for the period 1991 - 1995.
4. The future of IAEDB.

At the meeting of the Executive Committee, held in Bydgoszcz, Poland in April 1994, it was decided to establish a Strategic Plan Working Group to consider the future structure and activities of IAEDB. The group met in the UK in November 1994. Tony Best, who is leading the strategic plan process, will report. Members should note that they will be asked to participate in the Consultation Groups during the Conference. It will be proposed that the Executive Committee be empowered to implement agreed outcomes of the process.

5. Elections to the Executive Committee.

The Strategic Plan Working Group have proposed that the elections for membership of the Executive Committee not be held before or during the World Conference on this occasion but that the current members continue until the completion of the strategic planning process and the adoption of its outcomes. This is currently scheduled for the 1996 meeting of the Executive Committee which will be held in May in Vancouver, Canada. This proposal has been agreed by all EC members so far responding and no member has disagreed to date. It is proposed that the election of officers take place forthwith ie Chairman, Vice-Chairman and Secretary/Treasurer. In accordance with the constitution, this will take place at the next meeting of the Executive Committee on Thursday 13 July 1995.

6. Resolutions
7. Items for discussion.
8. Items to go forward to the meeting of the Executive Committee to be held at Cordoba National University on Thursday 13 July 1995, 1730 - 1930.
9. Any Other Business.

Any member wishing to submit a Resolution or an Item for Discussion is asked to ensure that it is with the Secretary/Treasurer by Friday 30 June 1995 at the latest. Address: Rodney Clark, c/o Sense, 11-13 Clifton Terrace, London N4 3SR, UK (Fax +44 171 272 6012)

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 _____

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